

Universidade de Lisboa
Instituto de Ciências Sociais



**A call for a broader citizenship:
Parent-led Autism Advocacy Movement in Portugal**

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Tese especialmente elaborada para a obtenção do grau de doutor em Antropologia
Especialidade de Antropologia da Saúde

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UNIVERSIDADE
DE LISBOA



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Abstract

This thesis is about Portuguese parents of children diagnosed with Autism Spectrum Disorders (from now on ASDs), defined as a set of neurodevelopmental disorders characterized by impairments in social interaction and communication skills and by rigid and repetitive patterns of behaviour (American Psychiatric Association 2013). It aims at understanding parents' caregiving experiences and expectations regarding their children's future, and at exploring their advocacy day-to-day practices and actions, and socio-political demands. I address, in particular, the ways in which parents use social media to deploy a different understanding of autism and to advocate for their children's rights in order to challenge misleading and disabling stereotypes. My fieldwork, indeed, focused particularly on parent-led online communities - namely Internet-based social networks (like Facebook) - where parents produce discourses about autism, share their experiences as caregivers, claim recognition for their knowledge, and call for their children's health and educational services. Support and advocacy online groups serve as collective platforms for parents to share what it means to be a parent to a child with autism and to confront themselves about the decisions they make when caring for their children, to interact with other parents and create relationships and friendship, as well as to deploy their expert knowledge. Social media, as technological tools and spaces, can entail the potential of mobilization, insofar as they offer an opportunity for people to claim for social change by sensitizing and encouraging others to take action. For these reasons, online autism advocacy proves, in my view, to potentially bolster parents to gain attention and visibility regarding disability issues, social discrimination and marginalization. I also investigate the impact of autism in parent's lives and explore the gendered practices of caregiving and advocacy within the family environment, as well as parents' ideas about diversity, inclusion, and citizenship.

Keywords

ASDs, online advocacy, disability, inclusive citizenship, neurodiversity

Resumo

Esta tese propõe compreender as práticas de cuidado e advocacia de pais de crianças com diagnóstico de Perturbações do Espectro do Autismo (PEA), um conjunto de distúrbios do desenvolvimento neurológico caracterizados por deficiências na interação social e na comunicação e por padrões rígidos e repetitivos de comportamento (American Psychiatric Association 2013).

Procuro explorar, em particular, as maneiras como os pais usam as redes sociais para desenvolver uma compreensão diferente do autismo e defender os direitos de seus filhos, a fim de desafiar os estereótipos incapacitantes. Meu trabalho de campo, de fato, concentrou-se nas comunidades on-line, nomeadamente grupos de suporte e advocacia baseadas na Internet (como o Facebook), onde os pais produzem discursos sobre o autismo, compartilham suas experiências como cuidadores, e reivindicam o reconhecimento de seus conhecimentos. Estes grupos on-line representam plataformas coletivas onde os pais compartilham o que significa ser pai e mãe de uma criança com autismo, confrontam-se com outros pais acerca das práticas de cuidado de seus filhos, interagem e criam laços de amizade. Usando as redes sociais como ferramentas e espaços de partilha, os pais mobilizam-se, na medida em que reivindicando direitos civis para os próprios filhos, exigem uma mudança das políticas sociais contra a discriminação social e marginalização das pessoas com deficiência. O trabalho de campo permitiu-me perceber as reivindicações políticas dos pais e as suas práticas de advocacia, e analisar as práticas de cuidado segundo uma perspectiva de género bem como as ideias dos pais sobre a diversidade, a inclusão e a cidadania. Através das minhas observações e participando nas actividades dos pais, proponho mostrar como o movimento de advocacia dos pais em Portugal tenta ganhar visibilidade e reconhecimento através do uso da Internet e dos grupos virtuais de apoio e advocacia ao fim de politizar as suas lutas e pedir um envolvimento coletivo. A este respeito, a minha dissertação mostrará como os pais denunciam as formas diárias de exclusão que os próprios filhos vivem, procurando de tal forma denunciar as práticas de discriminação das pessoas com deficiência e questionar o princípio da normalização que orienta as práticas institucionais da inclusão na escola e na sociedade em geral. A tese visa contribuir para o conhecimento antropológico sobre autismo e advocacia abordando também as questões da cidadania inclusiva e da neurodiversidade, uma visão que destaca a necessidade de não

discriminar as pessoas com PEA. Vou enquadrar a discussão antropológica em torno do conceito de inclusão e cidadania para realçar o desafio atual que todos nós como seres humanos e atores civis subscrevemos, ou seja a necessidade de proporcionar um novo cenário futuro onde as pessoas com deficiência têm o seu lugar. A perspetiva antropológica subjacente à minha pesquisa visa portanto alcançar um objetivo político e epistemológico. Ela propõe olhar criticamente e desafiar as construções epistemológicas, políticas e institucionais que sustentam, mesmo tacitamente, práticas de exclusão e marginalização do Outro. Ao revelar como a economia da cidadania se baseia numa hierarquia perigosa (e muitas vezes escondida) dos seres humanos, o conhecimento etnográfico contribui também para politizar a questão da deficiência e revelar as formas comuns em que as pessoas com deficiência ainda sofrem de discriminação. Enquanto sujeitos marginalizados, as crianças com PEA mostram, de fato, as tensões e as armadilhas que a sociedade põe no seu caminho. As práticas de advocacia dos pais e as suas reivindicações têm nesse sentido o objetivo de sensibilizar a sociedade para que possa reconhecer, praticar e garantir os direitos das pessoas com autismo. Este objetivo representa de facto uma possibilidade de emancipação para a nossa sociedade em geral.

Esta tese encontra-se organizada em uma introdução e em seis capítulos. No Capítulo I vou relatar a história da psiquiatria infantil portuguesa, concentrando-me na figura do psicanalista João dos Santos, pioneiro na geração profissional da psiquiatria infantil e na prática de saúde mental infantil. Em particular, proponho explorar a abordagem psicanalítica da psicopatologia infantil e os seus conceitos e realçar as instituições mais importantes relacionadas com o desenvolvimento da psiquiatria infantil em Portugal. O Capítulo II propõe investigar as condições que permitiram a identificação e emergência do autismo como condição psiquiátrica em Portugal no final do século XX e a maneira como o autismo foi primariamente descrito pelos profissionais de saúde mental da época. Esta exploração tem como objetivo contribuir para uma história local do autismo e ilustrar a criação da primeira associação de apoio ao autismo liderada pelos pais. No Capítulo III exploro as experiências cotidianas dos pais em viver e cuidar de seus filhos com autismo. Através dos relatos etnográficos, descrevo as razões pelas quais os pais decidiram fazer parte de grupos de apoio e as diferentes maneiras de ser ativistas. Nesta seção, apresento o principal grupo de apoio e advocacia on-line português liderado por pais de crianças com autismo - Os Amantes de Saturno - e exploro os principais tópicos que os pais discutem nesta comunidade virtual. O Capítulo IV examina as lutas de advocacia dos pais sobre escola inclusiva, serviços de saúde e apoio para a transição para a vida adulta. Esta análise mostra como as reivindicações políticas dos pais mudam em relação as

necessidades dos filhos desde a infância até a idade adulta. O envolvimento pessoal dos pais nas questões da deficiência é a origem de uma transformação da subjetividade dos mesmos pais que assim se tornam cidadãos ativos envolvidos na consciencialização pública das questões de justiça social e inclusão. O Capítulo V explora as práticas de cuidado a partir da perspectiva de género e aborda os discursos afetivos das mães sobre a maternidade e o cuidado dos filhos como um instrumento político para reivindicar o papel público de principais figuras do movimento de advocacia ligado ao autismo Portugal. O Capítulo VI analisa em primeiro lugar como as pessoas com autismo utilizam de forma diferente os artefactos tecnológicos - como dispositivos móveis e programas de comunicação aumentativa e alternativa (AAC) - para melhorar as suas habilidades sociais. Na sua seção final, o capítulo interroga criticamente a noção de “humano” para explorar as questões de cidadania inclusiva.

Palavras-chave

PEA, advocacia online, deficiência, cidadania inclusiva, neurodiversidade,

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List of abbreviations

- ABA - Applied behavioural analysis
ADHD - Attention deficit hyperactivity disorder
APPCA - *Associação Portuguesa para a Proteção de Crianças Autistas* (Portuguese Association for the Protection of Autistic Children)
APPDA - *Associação Portuguesa para as Perturbações do Desenvolvimento e Autismo* (Portuguese Association for Developmental Disorders and Autism)
APSA - *Associação Portuguesa Síndrome de Asperger* (Portuguese Asperger's Syndrome Association)
ARI - Autism Research Institute
ASDs - Autism spectrum disorders
CEMES - Centre for Multidisciplinary Studies - Ernesto de Sousa
CERCIS - *Cooperativa de educação e reabilitação de cidadãos com incapacidades* (Disabled Citizens Education and Rehabilitation Cooperative)
CESM - *Comissão de Estudos da Saúde Mental* (Committee on Mental Health Studies)
CNRS - National Centre for Scientific Research
CPS - Child Psychiatric Services
CSMIL - *Centro de Saúde Mental Infantil de Lisboa* (Center for Children's Mental Health of Lisbon)
DC: 0-3 Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood
DIR Developmental, Individual Difference, Relationship-based model
DSM - Diagnostic and Statistical Manual of Mental Disorders
FPDA - *Federação Portuguesa do Autismo* (Portuguese Federation of Autism)
IAACF - *Instituto António Aurélio da Costa Ferreira*
IAC - *Instituto de Apoio à Criança* (Child Support Institute)
ID - Intellectual disability
MUD - Movement for Democratic Unity
PDD - Pervasive Developmental Disorders
PDD-NOS - Pervasive Developmental Disorders-Not Otherwise Specified
SEN - [children with] Special Educational Needs
SPP - *Société Psychanalytique de Paris* (Paris Psychoanalytical Society)

NOTE:

Since my dissertation is in English and I want to provide the readers with a linear reading, I prefer to translate all foreign quotes. So, except as otherwise indicated all translations are mine.

A call for a broader citizenship

*To my grandmother
Grazia*

Introduction: Setting the scene

This thesis is about Portuguese parents of children diagnosed with Autism Spectrum Disorders (from now on ASDs), defined as a set of neurodevelopmental disorders characterized by impairments in social interaction and communication skills and by rigid and repetitive patterns of behaviour (American Psychiatric Association 2013). My main interest is, in particular, the understanding of parents' caregiving experiences and expectations regarding their children's future, their daily advocacy and their socio-political demands.

Autism is not a new topic in my academic path. In my Master thesis (Lo Bosco 2011), I described the scientific construction of the neuroscientific theory of the Mirror Neurons System (MNS), whose allegedly function in humans is to map the observed actions onto the observers' own motor system¹. Since human MNS is widely assumed to provide a primary mechanism both for understanding other people's actions and intentions and for imitating them (see Ferrari and Rizzolatti 2014 for a review), some scholars suggested that a "dysfunctional" MNS may underlie the social deficits observed in autism (Dapretto et al. 2006; Iacoboni and Dapretto 2006; Ramachandran and Oberman 2006). My aim at that time was to critically explore how neuroscience's technological advances offered a new theoretical perspective for the understanding of social interaction, intersubjectivity and eventually autism disorder. While meaning and explanation of ASDs are still controversial, with ongoing debates about diagnosis,

¹ In my Master Thesis "An anthropological reading of a scientific dispute. The neural approach to intersubjectivity according to the Mirror Neuron Theory" (Lo Bosco 2011), I addressed the "discovery" of a new class of neurons in the Macaque monkey's premotor cortex. While observing monkeys' brains, neuroscientists noticed that certain cells activated both when a monkey performed an action and when that monkey watched another monkey perform the same action, inferring that these neurons "mirror" the behaviour of the other (Gallese et al. 1996; di Pellegrino et al. 1992). Mirror neurons thus appeared to form a neural system linking the motor (execution) and sensory (observation) areas of the brain. Since experimental studies suggested that a similar system also exists in humans (Fadiga et al. 1995), scholars speculated about their possible role in social imitation, mind-reading, social interaction and empathy (Ferrari and Rizzolatti 2014). Since these neurons "mirror" the behaviour of the other, as though the observer were acting, scientists claim that they lie at the root of understanding others' actions and intentions (Gallese and Goldman 1998). Other scholars argue that they provide the neurophysiological mechanism for the development of our sense of identity and of our capacity to share our feelings and emotions with others, thus grounding our connectedness to others and our ability to empathy (Gallese 2001, 2009). In line with those hypotheses, some neuroscientists also argued that the social impairments displayed by autistic children could depend on a dysfunction of the mirror neuron system (Dapretto et al. 2006; Iacoboni and Dapretto 2006; Ramachandran and Oberman 2006). My Master project aimed at (i) critically exploring how technological advancements and theoretical developments in neuroscience offered new tools for thinking about social interaction, intersubjectivity and eventually autism, and at (ii) showing how autism draws a tension between (new) scientific epistemologies, the socio-historical context in which these tangle with and the ways Otherness and Normalcy are socially constructed and politically negotiated.

aetiology, and treatment (Silverman 2012), in the last decades media contributed to turning autism into a global phenomenon. At the same time, autism rights movement and parent-led advocacy associations - which developed since the 1980s - keep fighting for the recognition of people with autism's civil rights in order to challenge discriminatory practices, exclusionary processes and negative attitudes towards disabled people. Within these groups, parents demand education and health care access for their children, claim for the recognition of their expertise as caregivers, and promotes themselves as autism advocates.

Taking in consideration these aspects, my present dissertation addresses the ways in which parents of children with autism use social media to deploy a different understanding of autism and to advocate for their children's rights in order to challenge misleading and disabling stereotypes. My fieldwork focused particularly on parent-led online communities - namely Internet-based social networks (like Facebook) - where parents produce discourses about autism, share their experiences as caregivers, claim recognition for their knowledge, and call for their children's health and educational services. Social media, as technological tools and spaces, can entail the potential of mobilization, insofar as they offer an opportunity for people to claim for social change by sensitizing and encouraging others to take action. For these reasons, online autism advocacy proves, in my view, to potentially bolster parents to gain attention and visibility regarding disability issues, social discrimination and marginalization. My online fieldwork, then, has been crucial in order to address how support and advocacy online groups serve as collective platforms for parents to share what it means to be a parent to a child with autism, to confront themselves about the decisions they make when caring for their children, to interact with other parents and create relationships and friendship, to deploy their expert knowledge and "take action". Eventually, during the fieldwork, I also participated in face-to-face parents' initiatives, as well as interviewed parents, in order to investigate the impact of autism on their lives and to acknowledge the day-to-day ways in which they raise disability awareness and contribute to autism understanding. This helped me to explore the gendered practices of caregiving and advocacy within the family environment, as well as parents' ideas about diversity, inclusion, and citizenship. The articulation of all these different topics, which have been usually explored as separate levels (see Solomon 2010 for a review), represents an important quality of my work.

Moreover, by focusing on parents' point of view, listening to their stories and participating in some of their daily activities, I seek to make sense of their complaints and read their political

claims, which sometimes are unheeded. It is, indeed, thanks to the ethnography, to its thick descriptions of and attention to the ordinary course of people's lives, that the political nature of our actions gains visibility. In this respect, I will argue that, despite its fragmentation, parent-led autism advocacy in Portugal is a movement trying to gain a role in the process of policy-making thanks to those parents who, as civil actors, use social media to further politicize their struggles and call for collective engagement. In this respect, as my dissertation will show, parents denounce disabled people's daily forms of exclusion, stigma, and discrimination, and in doing so they question the principle of normalization that guides and permeates current practices of inclusion in social institutions (such as school and workplace) and in society at large. My local fieldwork, thus, aims to contribute not only to the understanding of current autism advocacy movement in Portugal but also of broader social and political issues such as social inequality, discrimination, social justice. Furthermore, my thesis tackles the issues of inclusive citizenship and neurodiversity, according to which autism is a natural human variation rather than a pathology or disorder. This view highlights the need to no longer discriminate nor normalize people diagnosed with mental disorders. Eventually, my idea of parents fighting for "a broader concept of citizenship" acknowledges the need for a re-valorization of subjugated or marginalized "subjects", such as people with autism.

The articulation between the ethnographic knowledge and theoretical perspective on inclusion and citizenship contributes to the understanding of the challenge that we currently endorse as human beings and civil actors, namely the need to develop a new possible future scenario for people with disability. The anthropological perspective underpinning my research aims at achieving a political and epistemological purpose. It helps to critically look at our epistemological constructions, policies and institutions and challenge one's own (hidden) practices of exclusion of the Other. By revealing how the economy of citizenship is based on a dangerous (and often hidden) supposed hierarchy of human beings, it also contributes to politicizing the issue of disability and to revealing the ordinary ways in which disabled people still suffer from discrimination. Insofar as children with autism and intellectual disability remain at margins of society, they show, indeed, society's own tensions and obscure traps. Yet, as marginalized subjects, they represent - even if through the intervention of their activist parents - powerful subjects claiming for social change. Their "recognition" is, indeed, a possibility of emancipation for our society at large.

Besides these considerations, there are other aspects supporting the relevance of my study. By exploring the advocacy among families of children with autism, my study looks at parents' production and sharing of knowledge in order to understand their collaborative efforts and political claims and to acknowledge their own practices of being chief advocates for their children's rights. In doing so, my research has the ambition to bring the attention of disability and anthropology studies on autism in the Portuguese context, where it has not yet been specifically explored as an object of study. The specific historical, cultural, political and economic conditions of Portugal posed, indeed, singular challenges to the establishment of the disability rights movement and to the spread of the social model of disability (a topic I will explore later). As a result, while in the UK and USA these events have historically played a crucial role in the politicisation of disability issues and in the development of disability studies, in Portugal the study of disability has been limited to the fields of psychology, medicine and education sciences, all areas in which the medical model has been dominant (Fontes et al. 2014:7). Portuguese social scientists have directed their attention to this area of study only recently, so that disability studies are considered an "almost non-existent" field in Portugal (idem:6). For instance, with the exception of the work of Bastos (2001), Portuguese anthropology did not produce a flourishing corpus of studies about disability, autism and advocacy. Most part of disability studies has been mainly produced in the field of sociology (see Salvado 2012 for a review), where scholars have recently started to explore disability with regards to issues of exclusion, poverty and social inequality (Pimenta and Salvado 2011) public policies (Capucha et al. 2004) social protection (Salvado 2008), and job policies (Viega 2006). Considering the historical difficulties and challenges explored by Fontes et al. (2014), this sociological scholarship has been particularly able in producing a collective work of great relevance (Hespanha et al. 2012; Martins and Fontes 2016; Nogueira and Portugal 2010; Portugal 2016; Portugal et al. 2010). My focus on online advocacy is also new for disability and anthropology studies in Portugal, as well as virtual ethnography, which stands as a new methodological approach for anthropological research on autism and disability in the country. Additionally, most of the demands put forward by disabled people's organisations in Portugal were used to be "first-level demands" (Fontes 2014:1403), that is demands which focus on basic rights needed to achieve a minimum standard of citizenship. My investigation on parents' demands for so-called "second-level demands" - demands that emphasise social and political issues - is thus central to the understanding of the changing discourses of disability politics in Portugal. Despite its informal or apparently scattered nature, parents web-based activism has the potential to improve traditional strategies of advocacy, as well as to spread the need of a

broader conception of citizenship able to include people with autism. Hence, the focus on the debate regarding the relationship between citizenship and intellectual disabilities (a topic I will explore in Chapter VI) identifies a crucial issue for current research on medical anthropology.

My dissertation also confronts itself with a challenge which anthropologists are used to, that is how to describe and unveil the uniqueness of human beings' experiences without hiding the powerful commonalities that allow them to gather and share the sense of belonging to a group. For instance, each of the core impairment areas of ASDs (communication, social interaction, repetitive behaviour/restricted interests, sensory processing and learning styles) presents differently in every child, which makes the experience of autism highly variable from child to child. Also, children with autism span a different range of intellectual (dis)abilities. As a result, parents' experiences about living with and caring for their children are multiple, as well as the rights, needs and services they claim and demand as their advocates. In this respect, while providing an overview of autism advocacy movement in Portugal, my study highlights the anthropological relevance of intergroup heterogeneity and diversification.

Theoretical framework

In the following section, I will trace the theoretical framework of my dissertation, by focusing on the different academic areas it tackles.

Anthropology of disability and autism

Despite some few pioneering works - such as Ruth Benedict's (1934) study of cross-cultural conceptions of epilepsy - anthropology is relatively new to disability studies. It was the spread of the disability rights movement in the 1960s and 1970s that "sparked the interest of medical and cultural anthropologists" for the "otherness" of disability (Reid-Cunningham 2009:101). While some anthropologists contributed to the understanding of disability in different social and cultural contexts, others produced ethnographic studies that directly engaged with disabled people in order to document their own experience (see Ginsburg and Rapp 2013; Reid-Cunningham 2009 for a review). Overall, anthropological approach to disability is informed by a "social model of disability" (Goodley 2001; Oliver 1996, 2013), which considers "disability" as the product of social and material determinants that *dis-able* people and exclude them to fully participate in society. This perspective arose from disability scholars' critique to the medical model that, by ascribing disability to individual's physical and cognitive impairments, naturalizes society's discriminatory attitudes towards people with impairments and hides its

failure to provide adequate and appropriate services. By acknowledging disability as “the result of negative interactions between a person with an impairment and his or her social environment” (Ginsburg and Rapp 2013:54), anthropology has addressed society’s normative values and their correlation with social inequality and discrimination. The emphasis on social and political dimensions of disability had important implications in terms of people’s empowerment and citizenship, insofar as it allowed people to mobilise against social exclusion and to reconfigure their identities against those values that disqualify them as lesser people. Several anthropologists, for instance, used auto-ethnography to offer their reflexive accounts of how they experienced diverse forms of disablement (Martin 2007; Murphy 2001) and to support the idea that disabled people are not mere “objects” of charity, medical treatment and social protection but “subjects” with the right to be fully participating citizens.

Among the topics addressed by the anthropology of disability, autism increasingly emerged as an object of research. Conference panels, special issues, edited volumes, and ethnographies marked a substantive contribution of anthropology to autism understanding and opened up new grounds for rethinking autism and disability issues.

Psychiatry and allied disciplines usually refer to autism as a neurodevelopmental disorder characterized by deficits in social communication and social interaction. Conceived in this manner, autism is supposed to preclude meaningful social behaviours and to negatively affect how people perceive the world and interact with others. To challenge this view, several anthropologists started to address autism by rejecting the narrow confines of what constitutes human social functioning, and by showing the complex ways in which autistic children and adults participate in and contribute to their societies. For instance, Ochs and colleagues’ ethnography (2004) on so-called high-functioning autistic children was a pioneer in recognizing people with autism as “participating members of social groups and communities” (idem:147). By critically analysing the ways in which biomedical knowledge assessed social competence in autism, they proposed indeed to “amplify the notion of social functioning to specify socio-cultural as well as interpersonal knowledge and skills” (idem:154). In doing so, they acknowledged how people with autism do display social competencies and difficulties in relation to socially and cultural ordered expectations of behaviour (idem:157-58). Similarly, Ochs and Solomon (2010) defined autistic sociality as part of a range of human possibilities for the fundamental practice of “social coordination with others” (idem:69). These works

significantly contributed to acknowledge autistic people's "different" social capacities and ways of interactions.

In this respect, in their introduction to the special issue "Rethinking Autism. Rethinking Anthropology", Solomon and Bagatell (2010) argued how anthropological studies of autism contributed to larger debates about epistemology and understanding of human diversity. Similarly, Solomon (2010) identifies three major contributions of anthropology to the study of autism: (1) a conceptualization of inter-subjectivity as practice-based, (2) an interpretive stance focusing on the lived experiences of affected persons and (3) a methodology approach that investigates in situ the everyday practices of people with autism and their families (Solomon 2010:244). Recently, Davidson and Orsini's edited book (2013) reintroduced anthropology's commitment to challenging longstanding views of people with autism as lacking in basic human capacities for social interaction and empathy. Anthropology's commitment to understanding the experience of disability within a ableing framework results in the acknowledgement of the different living experience of autistic people autism as a form of human diversity. In this respect, anthropology's epistemological turn to the corporeal (Csordas 1990, 1994) has brought attention to the experiential and phenomenological dimensions of disability. For instance, the focus on the experience of living with autism informed those anthropologists who offered their emic accounts of being an autistic parent (Prince-Hughes 2004, 2010) or of having a child with autism (Grinker 2007; Haldane and Crawford 2010). Other studies have brought attention to parents' perspective by addressing their suspicion surrounding supposed links between vaccines and autism (Kaufman 2010), by showing their daily negotiations of autism's diagnosis, services and interventions (DePape and Lindsay 2015; Ooi et al. 2016; de Wolfe 2014), as well as their collaborative or conflictual attitudes with doctors and scientists (Silverman 2012). Other scholars, more interested in the empowering aspects of virtual communities, explored online autism self-advocacy movement, providing a key perspective on autistic people's citizenship practices and political agency (Bagatell 2010; Bumiller 2008; Dekker 1999; Jordan 2010). These studies hold the Internet as space where autistic people can more easily express their own self and share their way to experience the world, increasingly challenging the deficit perspective on autism. Anthropology has also investigated the manifold implications of the recent expansion of the autism spectrum in the field of autism research, treatment and advocacy (Eyal et al. 2014), as well as addressed cross-national analyses of autism social movements (Cascio 2015; Orsini and Smith 2010).

Engaging with the Internet and social media networks

The Internet and social media have had wide cultural, social and epistemological impacts on our ways of conceiving identity, sociality, friendship, and community formation. Several collective works contributed to the understanding of “virtual” or “network” society’s features and implications (Barney 2004; Castells 2010; Graham and Dutton 2014; Noor Al-Deen and Hendricks 2012; Woolgar 2002). Social media studies explored issues such as people’s online presence, virtual self-presentation or online “true-self” (Bronstein 2013; Marriott and Buchanan 2014; Orsatti and Riemer 2012; Utz 2015) as well as people’s personality in online self-disclosure (Chen et al. 2017) and its impacts on offline identity (Yup Lee 2014). While some researchers showed social media’s positive influence on social relationships by addressing, for example, the feeling of social connection in virtual reality (Baym 2010) and the changing nature of friendship and intimacies following the rise of social networks such as Facebook (Chambers 2013; Ellison, Steinfield, and Lampe 2007), others explored the dark side of social networks’ consumption (Fox and Moreland 2015) such as lack of privacy, social anxiety, depression (Alkis, Kadirhan, and Sat 2017; Primack et al. 2017), social media fatigue (Bright, Bardi Kleiser, and Grau 2015) or cyber-bullying (Ho, Chen, and Ng 2017). This broad range of topics reveals the diversity of people’s use of the Internet, as well as its multiple implications and relevance for academia. However, most part of these studies considers social media and the Internet as a virtual “other” world or as a (good or bad) medium that acts on and influences offline - that is, *real-life* - experiences and practices.

Anthropology explored social media and virtual communities in different ways and has been especially able to account for the complex integration between online and offline worlds. For instance, Boellstorff’s “Coming of Age in Second Life” (2008) is acknowledged as the first classic ethnography of the virtual world. The author conducted more than two years of fieldwork in Second Life by means of his avatar “Tom Bukowski” who lived among and observed its residents. He applied anthropology methods to study this new human environment and its many aspects, including gender, race, sex, money, conflict, the construction of place and time, and the interplay between the self and the group. Bringing anthropology into a territory never studied before, Boellstorff showed how humans have always been virtual and that also virtual worlds arose from human beings’ elemental need of relating and creating communities.

Thenceforth, several anthropology scholars collaborated in collected works exploring the digital culture and online social networks (Miller et al. 2016; Miller and Horst 2012;

Papacharissi 2011). Confronted with the fast-moving digital world, researchers have provided diverse handbooks of virtual ethnography (Boellstorff et al. 2012; Coleman 2010; Collins and Durington 2015; Hine 2000, 2005b, 2015a; Miller and Slater 2001; Pink et al. 2016) and practical guides on how to design or adopt new digital technologies - such as online questionnaires and interviews, digital video, social networking websites, and blogs - for social research (James and Busher 2009; Murthy 2008). On a more theoretical level, Ginsburg (2008) claims “digital age” shaped a new anthropological framework for understanding globalization, media, culture, and community. Similarly, Hine (2005a) argues how the “cyber-social-scientific knowledge” that has been produced in our era has been a valuable reflexive opportunity for anthropology. Also, Boellstorff (2011) recognizes how the virtual world intimately transformed our understanding of the body and reconfigured our conceptualizations and experiences of embodiment (idem:504). Taking into account the emergent forms of ethnographic practice and knowledge driven by social media, this body of literature provided comprehensive analyses of the Internet culture, platforms and uses as well as of the social, political and cultural impacts of contemporary experiences of virtuality.

Digital anthropology has insightfully revealed “the mediated and framed nature of the non-digital world” (Horst and Miller 2012:13), keeping the use of the term virtual just for practical reasons. As digital anthropologist Boellstorff pointed out “the virtual and the actual are not blurring, nor are they pulling apart from one another. Such spatial metaphors of proximity and movement radically mischaracterize the semiotic and material interchanges that forge both the virtual and the actual” (Boellstorff 2012:56). Alongside offline worlds, online worlds are, thus, another arena of experience and action. As a result, the use of the word real, as it were opposite to virtual, risks fetishizing offline world as a site of retained authenticity. Indeed, we live and interact with people within different and simultaneous landscapes of experience that shape and nurture our subjectivities, memories and actions. As people’s everyday life is both online and offline, the Internet and social networks can no longer be considered as an “alternate” world but rather as parallel means and places through which we associate and interact (Wellman and Haythornthwaite 2002). Accordingly, social media and online communities are broadening our opportunity of sociality, which is now intrinsically digital or web-based. In this regard, since we choose the degree of privacy of our online social networking and the conditions according to which we interact with other cyber users in our everyday life, social media has created a so-called “scalable sociality” (Miller et al. 2016:3–6), meaning that there is always a scale from

the closest to the most open way of exposing ourselves and interact in virtual reality environments.

As I mentioned before, beyond more traditional methodology (such as snow-ball method and participant-observation), I also employed social networks and virtual groups (especially Facebook-based) in order to gain access to autism online advocacy groups and create a network of acquaintance. These online groups allowed me to explore the ways in which parents share their everyday experience, connect, find support and call for autism rights advocacy. In what follows, I will then take into account of those studies that acknowledge virtual social networks as useful methodological tools able to open up for new pathways of knowledge. According to Parks (2011), by using computer-mediated social networking sites people create “virtual communities”. As a result, social networks sites such as Facebook are described as “networked publics” supporting sociability (boyd and Ellison 2007:221). This means that they are “simultaneously (1) the space constructed through networked technologies and (2) the imagined collective that emerges as a result of the intersection of people, technology, and practice” (boyd 2011:39). As a space allowing people to connect for social, cultural, political and civic purposes, Facebook tangles with the social and material frame of our everyday life (Horst 2015), as well as with our offline temporalities and locations (Hine 2015a). Digital anthropologists have indeed described social networks as “localities” (Pink et al. 2016) to highlight how they belong to the shared context we inhabit. Localizing virtual communities is thereby prominent in order to acknowledge its local features, uses and practices (Postill 2008). For instance, Miller’s “Tales from Facebook” (2011) are located in the Trinidad islands insofar as the author explored how the different aspects of the island’s culture reveal themselves in and were mediated through Facebook itself. This shows that when anthropologists look at online social networks as ethnographic sites they consider of crucial importance to closely look at the local context(s) in which these are embedded in.

The attention to the local socio-cultural, political and economic background of social media reveals how the Internet can also mirror formerly existing inequalities (Taylor 2014). In this regard, social networks and again especially Facebook played a crucial role in organising uprisings, garnering support in denouncing inequality and in spreading virtual activism. While some scholars addressed the transformation of politics following the use of digital media and social networks for political and civic engagement (Postill 2012), others tackled how new technologies altered the nature of political agency as well as community and political

representation (Holmes 1997). The “virtual public arena” or “blogosphere” (Keren 2006) has indeed transformed the traditional way to express and perform politics insofar as the Internet has increasingly become an instrument of activism (Blood 2001; Hands 2011; Marichal 2013; McCosker 2015). Therefore, people’s online presence represents not only a way of constructing identity and shaping social interactions but also a discursive and political strategy for exercising agency within a local context.

Social media and disability: the emergence of online support and advocacy groups

Digital media and technologies break traditional barriers to communication and interaction and turned in a useful medium for disabled people to mediate civic engagement and barriers they faced. In doing so, disabled people become key protagonists of new and alternative forms of collective online political activism, bringing an unprecedented understanding of disability issues. Scholars explored the social construction of disability in new media (Goggin and Newell 2003), acknowledging the role of networked technologies (such as social networks, blogs, wikis, video-sharing sites) and digital devices (such as eBooks, tablets, mobiles and apps) in shaping disability’s experiences (Ellis and Kent 2011). In this regard, Ginsburg (2012) examined how digital technologies enable disabled people “to engage in a first-person discussion of their world and experiences - often asserting an alternative sense of personhood (...) and to enhance the possibilities of forming community for those who have difficulty speaking or sustaining face-to-face conversation” (idem:102). Thanks to social media, indeed, disabled activists have the chance to engage in the public sphere and challenge narrow or stereotyped representations of their own lives. Similarly, drawing on a case study of autism activism in Canada and in the USA, Orsini and Smith (2010) explored the role of social movements in the policy process and the range of ways in which autism activists both deploy and contest expert knowledge. Nevertheless, researchers have also analysed the challenges that social media represents for the social inclusion of people with disabilities, opening up debates about technology’s accessibility and design, online discrimination, and social justice (Ellis and Kent 2017).

Since ASDs cover a large spectrum of symptoms, skills, and different levels of social, communication, and behavioural challenges, it is worth clarifying the different impact and uses of digital technologies for people generally considered “on the autism spectrum”. On the one hand, visual and mobile devices and alternative communication programs are mainly used as technology-based “therapeutic” tools for individuals with severe forms of autism as a way to

improve their social and communication skills (Aresti-Bartolome and Garcia-Zapirain 2014; Arthur-Kelly et al. 2009). On the other hand, digital media such as social networks and blogs represented a comfortable communication medium and a means of self-expression and interaction especially for those autistic people diagnosed with former Asperger syndrome (Haney and Cullen 2017; Jordan 2010). By drawing on first-hand accounts and autobiographies of people with autism, scholars suggest the existence of distinctive “autistic” styles of communication and sociality (Davidson and Henderson 2010; Hacking 2009a; Happé 1991; Ochs and Solomon 2010). Also, scholars who have been diagnosed with autism addressed from a subjective point of view the formation of an “autistic culture” online along with the emergence of an autism self-advocacy movement (Davidson 2008; Dekker 1999; Prince-Hughes 2004). According to Davidson and Parr (2016) people with autism “inhabit online spaces because off-line environments can feel sensorially overwhelming, emotionally uncomfortable, socially stigmatizing and so, disabling, rendering those with autism disorder and mental health difficulties vulnerable and excluded in many different ways” (idem:63). Virtual space emerged thus as an enabling geography for disabled people (Chouinard, Hall, and Wilton 2016) and a space of commonality where the difference is recognized and respected (Bertilsdotter Rosqvist, Brownlow, and O’Dell 2013). As the Internet gained a political meaning for people with autism insofar as it became a medium to advocate for their rights, scholars explored the role of online communities for people with autism who claim for a collective autistic identity and use blogs and forums as political platforms in order to perform their role as self-advocates (Bagatell 2007; Parsloe 2015).

People’s use of the Internet and social network sites to raise public awareness about their health condition, promoting understanding and turning “private troubles” in public issues, is not a new phenomenon. Scholars have already highlighted the potential of the Internet as a medium of activism for people with HIV/AIDS (Gillett 2003), as a place where breast cancer patients emphasize a sense of common struggle (Orgad 2006) or where people with diabetes educate themselves and others about living with the condition (Tirthali 2012). Online support groups for people with health conditions are now quite popular (Turner, 2017), facilitating the creation of friendship, the sharing of personal stories and the participation in discussion boards. These support communities provide emotional support and information not only to patients as in the case of self-support groups (Chung 2014; Mehta and Atreja 2015) but also to their parents and relatives (see Doty and Dworkin 2014 for a review). As a syndrome diagnosed during childhood, autism often elicits strong emotional reactions from parents. As a result, autism

support groups have shown to be a helpful way for these parents to learn from and support each other as well as to cope their children's needs. Several studies identified benefits for parents involved in both offline (Bitsika and Sharpley 1999; Mandell and Salzer 2007; Solomon, Pistrang, and Barker 2001; de Wolfe 2014) and online support groups (Carter 2009; Clifford and Minnes 2013; Jordan 2010). Anthropology showed that these groups also represent useful platforms for parents to advocate for their children's health and education rights (Falkmer et al. 2015; Rehm et al. 2013; Silverman 2012; Wright and Taylor 2014), as well as spread public awareness about autism and directly engage with scientific knowledge and the political establishment (Feinstein 2014; Langan 2011). As Jordan (2010) summarized:

Online discussion forums function as supportive communities, helping to alleviate symptoms of autism spectrum disorder and reducing the isolation experienced by parents and individuals with autism. The Internet offers fund-raising opportunities and increases research efforts. The Web has empowered individuals with autism and their families to advocate for themselves, through the use of online blogs and forum groups. (...) However, concern should be raised for individuals with low-functioning autism and of families of low socioeconomic status. Families living close to the poverty line are quickly left out of autism discourse if they do not have access to the Internet and other resources, and individuals on the low-functioning end of the spectrum are less capable of self-expression (idem:224-25).

Methodology

During my fieldwork, I have interacted with and interviewed parents of children with autism at autism-related official conferences and events, as well as at informal gatherings in public or private spaces. Apart from spending days interacting face-to-face with them, I have dedicated a significant portion of my fieldwork to virtual groups because several parent-led advocacy groups are located on this platform. Parents use Facebook's support groups as a tool for spreading information, asking questions, and helping other parents with their advice. Some of them use it also for more engaged civic purposes, such as for raising awareness about autism and disability rights, for promoting autism-related conferences and advocacy events, as well as for gaining visibility as activist parents. Social networks technology, indeed, provides parents with a range of affordances (boyd 2011; Hine 2008) such as new communicative possibilities and agency's opportunities that parents can handle within their broader social context. As a result, Facebook-based networking reinforces the sense of community of parents' support groups, which are founded on common interests and experiences due to having a child

diagnosed with autism. Among its practical benefits, Facebook friendship represents an opportunity to meet new people, as well as to maintain and solidify existing offline connections which could not be nurtured with everyday interaction (Ellison et al. 2007). In this sense, social bonds and friendship between parents emerge, are shaped and strengthened online.

Bearing these points in mind, the methodology supporting my research is based on ethnographic methods that emphasize participant observation and in-depth interviews, including online research methods (Horst and Miller 2012) to investigate the potentials of virtual groups for advocacy (Karpf 2010; Postill 2012). Referring to the literature on online research approaches I mentioned before, I have elaborated my own method of (n)ethnography, in line with what Kozinets (2010) has labelled a “specialized form of ethnography” adapted to the Internet. Practically speaking, I have broadened my ethnographic know-how to incorporate Internet-mediated social data, as suggested by several anthropologists who have investigated online communities (Bowler Jr 2010; Kulavuz-Onal and Vásquez 2013; Wilson and Peterson 2002). The complementarity between online and offline domains of experiences implies that in my (n)ethnography the digital has been “de-centred”, meaning that I have not exclusively used a digital method. Digital ethnography is, indeed, defined as a processual methodology (Hesse-Biber and Griffin 2013; Hine 2005b, 2015b), in this sense that it is not a bounded research method or technique but instead, it is open to other influences and disciplines.

By using Facebook, I have gained access to parent-led advocacy groups in order to further my understanding of their claims, practices and shared experiences and to connect with parents when an offline meeting was not possible. I have not used those groups as a content platform or as an archive where to gather data. Rather, I have actively participated as a user in online groups in order to familiarize with parents, discuss the content they were posting, as well as arrange a meeting or an interview. By investigating how parents use the Internet and which content they spread for their advocacy purposes, I have acknowledged Internet-based parental groups as part of the local autism advocacy movement in Lisbon. My research on Facebook, indeed, has tangled with my offline analysis, and the two approaches have mutually influenced each other. This interlinked way to conduct fieldwork has given me the opportunity to meet a range of different people (men and women, older and younger) and to deepen my understanding of their everyday life’s perspective, shading light on the close relationship between parents’ online and offline presence and raising topics that would otherwise be lost or unexplored. For instance, the online fieldwork has allowed me to observe how a particular conversation topic

circulates through the community, sometimes even revealing its ambiguities and strengths. Similarly, an online post often engenders long comment threads unrelated to the original post, underlining how online interaction is often able to turn into a conversation on broader or related topics.

In more details, intermittently between January 2013 and February 2016 I have informally met and eventually in-depth interviewed 19 parents (15 mothers and 4 fathers) of children on the autism spectrum². I have approached 9 of them thanks to the “snowball method”, by the word of mouth with friends and colleagues and through the APPDA (the major Portuguese autism association). I have reached the other 10 parents through the Internet as they were users and members of online parent-led autism advocacy and support groups. At this regard, from March 2014 I have created a “professional” account on Facebook and started to regularly follow the activities of several online autism-related groups (*Autismo Portugal, Mães Especiais, Autismo Pais em Rede, Pais do autismo, Vencer Autismo, Dar-Resposta, APPDA-Lisboa, Federação FPPDA*), as well as online disability and parent advocacy associations (*Pais em Rede – Associação, Media e Deficiência, Associação de Pais pela Inclusão*). These groups have been the most *active*, showing a greater visibility not merely because of their virtual traffic or their number of subscribers, but above all because of their reputation and relevance for parents. From April 2015 to February 2016 (with exception of the months of July and August) I have eventually focused my (n)ethnography on the *Os Amantes de Saturno*, one of the main online advocacy and support groups for parents of children with autism existing in Portugal.

While I have had the chance to meet some parents on more than one occasion - for instance during autism-related events, informal meetings as well as in their own homes - others have agreed to meet me just to release an interview. The research has involved parents from different social and economic environments in order to avoid a fixed population bias and collect stories as much diversified as possible. My interlocutors comprise parents of different age (most of them in their forties), employment, and marital status. Out of 19 parents interviewed, six parents work full-time, six have a part-time or occasional job while seven are unemployed. Only eight parents are married or have a partner, and one was a widow. Among the other ten divorced parents, seven are single-mothers, one is a single-father and two (one woman and one man) have a new partner. Only one father has a daughter diagnosed with ASDs and only two married

² In Chapter III I will illustrate with more details my fieldwork access approach and the temporal stages of my research.

parents have one or more other children beyond the child on the autism spectrum. Together with parents' biographical diversity, also individuals diagnosed with ASDs - aged between 4 and 20, being only one adult male aged 42 - show peculiar "autistic" features and co-morbidity such as ADHD (Attention-Deficit/Hyperactivity Disorder), Tourette's syndrome, dyspraxia, dyslexia and epilepsy.

For practical reasons, I have usually started the interviews with sample questions concerning - among other topics - the child's medical history, parents' experience with caregiving and advocacy, their experiences with public space, as well as their expectations for the future. During the fieldwork, I have taken handwritten notes and digital audio notes, which I eventually saved into my online cloud storage. I have also personally translated from Portuguese to English all the audiotaped interviews, trying to remain true and accurate to the sense of the original speech and to the information it contains. All the names used in this document, except the APPDA and the group *Os Amantes de Saturno*, are pseudonyms.

Methodological issues

In what follows, I will report some methodological issues that emerged during the fieldwork.

The interlaced realities of fieldwork's interactions

As I have already mentioned, besides local associations, parents of children with autism use the Internet and social networks such as Facebook to personally engage with autism advocacy. As an ethnographer, I have reached relevant and qualitative insights from this media as it features prominently in parents' lives and practices. Yet, I have often clashed with virtual world's side effects, such when Wi-Fi-crash suddenly interrupted an intense online exchange with a parent or when on the contrary since media keep us connected almost during all day, my interlocutors and I have been virtually always on call. As a result, getting in and out of the field has been very challenging for me. Given the complementarity of online and offline realities, I have attempted, also in my writing, to recreate the fluidity between offline and online parents' discourses and practices of advocacy. From my observations, online interactions are equally sincere and "real" than the offline ones, and virtual reality has often allowed parents to easily speak about more intimate and personal issues. The online physical distance did not hamper people's emotional closeness. Furthermore, although they do not seem to concern with any physical displacement, online interactions tangled with people's physical environment and

relate to the encounter's spatiality. Interacting online has meant to me to always inhabiting a specific setting, with its social, emotional and moral features.

Temporality of fieldwork

As an ethnographer, I struggled to find an everyday pace within my field. To temporally embedding oneself in the field is not, indeed, a simple task. In this respect, temporality issues affected two specific aspects of my research practice: the process of getting in and out the fieldwork and the planning of meetings and interviews. Anthropologists usually spent a considerable amount of time to gain fieldwork's access (Johl and Renganathan 2010). While I had no particular difficulties in get acquaintance with my offline fieldwork, in the (n)ethnography there is no a clear geographical process of "getting in and out" from the field as happens in the more traditional type of ethnographic experience. As a result, sometimes I found myself doing research because a parent launched a relevant trending topics discussion online or she or he contacted me and started a conversation. Furthermore, despite anthropological fieldwork is based on a long-term stay, it is inevitably framed within a limited period. Nevertheless, by doing my research "at home" (in the same place where I lived) I have virtually postponed the date on which "get out" from the fieldwork. I often subordinated the period of fieldwork to the contingent availability of parents, regardless of my research chronogram. Parents usually dedicate the bulk of their time to raising and caring their children with autism so that I found it both problematic and frustrating that basic arrangements such as planning a meeting or an interview even weeks ahead seemed almost impossible. I soon realized that instead of complaining about my difficulties of planning, it was a question of "incorporating a constant anticipation of contingency" (Frederiksen 2008:9). Autism-related public events or conferences created the conditions and then possibility to encounter parents, speak with them and even to arrange a deeper conversation right away, while online interactions helped me to get or keep in touch with parents during the time and to reach them more easily when their availability was scarce.

Dealing with online privacy and intimacies

New media and digital platforms are increasingly intersecting with our daily lives and they comprise a variety of distinctive ways to share, connect and communicate our intimacy. In my fieldwork, I eventually crossed parents' intimacy practices and relationships with regard to kinship, affection, body, dis/abilities, friendship, gender. All these practices are materially displayed (that is, described and narrated) online thanks to the affordances of Facebook as a

medium intersecting with our intimacy. Chambers (2013), for instance, developed a theory of “mediated intimacies” by exploring the ways people engage with social media to build, maintain and exhibit personal networks. She argued indeed that digital communication technologies are contributing to new ideas and experiences of intimacy, friendship and identity through new forms of social interaction and new techniques of public display. Also, I acknowledged how privacy and intimacy affected my personal experience as a researcher and human being. Conducting online research enriched my understanding of my object of study and gave new meaning to the field experiences, but also elicited some ethical challenges. As a Facebook user, I could virtually have an “uncontrolled” or unlimited access to my interlocutors’ information, friends, photos and old posts. Hence, the use of an online personal profile demands that the ethnographer continuously emphasises her role as a researcher, since “[Facebook] creates new zones of privacy and intimacy and new scope for projecting a public persona” (Kirmayer, Raikhel, and Rahimi 2013:173). In what follows, I will address in particular the exposure of parents’ intimacies, the blurring borderline of their own private spaces (homes) and relationships (children, partners, relatives) once displayed online, as well as my own intimacy exposure once my interlocutors often solicited me to disclose my personal experiences or opinions.

Parents

Protecting the identities and privacy of my interlocutors - especially those encountered in online social networks - was a guiding concern in my fieldwork. But gaining informed consent was easier in the event of a face-to-face meeting with parents rather than in online interactions. At this regard:

“Individual and cultural definitions and expectations of privacy are ambiguous, contested, and changing. People may operate in public spaces but maintain strong perceptions or expectations of privacy. Or, they may acknowledge that the substance of their communication is public, but that the specific context in which it appears implies restrictions on how that information is - or ought to be - used by other parties” (Markham and Buchanan 2012:6).

As a result, as soon as I gained access to online parent-led groups I introduced myself as an anthropologist doing research on autism advocacy. In the “about section” of my Facebook profile, I published a summary of my research proposal and added my institutional email in case parents needed to contact me. When I addressed specific questions related to my research

through my Facebook profile, I always demanded parents' agreement to use their answers and information for my thesis by writing them private messages. I never considered my interlocutors' Facebook "wall" (the area on a profile where friends can see and post thoughts) as a box of public data, even when there were no privacy settings restrictions and the profiles were public. Since Facebook data use policy requires getting consent even for gathering public data, I used the information from online public profiles, pages or groups only after getting the consent of who posted the content. Also, I always made sure that my interlocutors were aware of where and how I will have report their statements. To do so, I sent inbox messages to every parent with who I made new "friendship" on Facebook explaining briefly my research, what kind of interest moved me to be part of the online network and asking permission to use in an anonymous form our future online conversations and inbox messages for research purposes. In the event that I eventually met face-to-face some parents that I first met online, I request to renew their informed consent. In this way, I obtained the permission to publish quotes from in-depth interviews, informal encounters, online public and private dialogues and status updates that appear in this thesis.

Children

Because of the trust and acceptance gained from fieldwork's several months of acquaintanceship, parents often told me their children's innermost occurrences and matters. Although I did not deal directly with children with autism, during the research I met them during my meetings with parents, who also posted online their children's stories and images. In this case, the shareable and long-lasting nature of children's online presence raised a host of questions about their privacy. I was concerned, in particular, about a parent's freedom to publish, as well as the child's right to her privacy. At this regard, Steinberg (2017) illustrates the perils of so-called *sharenting* "a term used to describe the ways many parents share details about their children's lives online" (idem:842). In online support groups for parents, sharenting is a way to support each other, explore new parenting strategies and share their children's common experiences and needs. In these communities, parents describe their child's intimate stories and issues in order to ask for advice or support, share their personal experience, or raise crucial questions concerning her health. Similarly, they share children's photos to simply apprise other parents about their children's growth and accomplishments. As might be expected, an implicit ethical sense guides sharenting in autism support groups in order to protect and respect children's privacy. Beyond questions of security or privacy, sharenting has implications also for the practices of parenting. As caregivers, parents feel empowered to share

their knowledge and expertise with other parents, friends, and distant relatives. However, this could also pose a threat to a child's sense of autonomy over her developing identity, since parents did not ask any permission before sharing her own intimacy. While some children with autism may have difficulties in engaging with others and making decisions for themselves, others are able to perceive their sense of self, as well as to make choices. These observations led me to critically think about how online sharing might affect children. As a result, whenever I deemed it necessary, I personally decide to do not report intimate information that could negatively affect - in my opinion – children's well-being, privacy and ease.

Me as an ethnographer

As I mentioned earlier, in order to investigate online parent-led autism advocacy groups and to protect the anonymity and privacy of parents and their children, I created a specific Facebook profile. Beyond having my real name, my profile reported also that I was an anthropologist working on autism advocacy. Long-term ethnographic fieldwork involves a deep and honest engagement in the lives of my interlocutors. When deemed appropriate, indeed, I sincerely expressed political and moral opinions, as well as displayed the emotions elicited by fieldwork itself, believing that this could not damage but instead nurture the bond with my interlocutors. During our conversations, it was not unusual that parents asked me about my interest in autism considering that I do not have a child nor a relative with autism. The fact of not be a mother has sometimes created an unpleasant distance especially with mothers who questioned my ability to truly understand what it was to live with, care and advocate for a person with autism. However, it has also been a way to create complicity with those parents who granted me the opportunity to listen to their own experiences.

Sensing the field and giving sense to emotions

Parents' experiences in caring for and being chief advocates for their children with autism elicit a very broad range of emotions, from anxiety, frustration, fear, uncertainty, concern, responsibility, self-confidence, fighting spirit, and courage. The bodily and verbal language through which they describe their stories could be, thus, extremely moving. Similarly, during the research, I also brought with me my own emotions and sensitivity and inevitably shared them with my interlocutors. Anthropology scholarship has for a long time now acknowledged emotions as embodied experiences of our relational life (Abu-Lughod and Lutz 1990; Lutz and White 1986; Pussetti 2005a; Rosaldo 1984). As a relational practice, also the ethnographic encounter arouses, and is imbued with, emotions insofar as people involved (the ethnographer

and her interlocutors) share their stories and engage in a relationship that creates meaning and emotionally shapes each other world (Beatty 2005; Davies and Spencer 2010). As a result, emotions influence the fieldwork in several ways: they affected our interactions, mutual understanding and knowledge exchange. In this respect, Ruth Behar (1996) addresses the question of researcher emotions and the false mythology of detached research in her book “The vulnerable observer”. Beyond designing research strategies for the study of the affective dimensions of our relational life (Stage 2015), several scholars also explored how sensory, emotional and affective relations form an integral, if often invisible, part of the process through which social researchers engage with, produce, understand and translate their research (Fraser and Puwar 2008).

To take into account the fieldwork’s emotionality helped me to critically reflect on my own emotionality and involvement with people, as well as to deepen my understanding of the fieldwork itself. At this regard, Wikan (1992) argued how the power of resonance represents an effective way of observing, participating with, and understanding the Other in the ethnographic field, allowing us to engage with people’s concerns. Acknowledging emotions as a valid and powerful way of understanding the field means to recognize the fundamentally relational nature of the ethnographic encounter. For instance, Spencer (2010) referred to the “field” not as a geographical space but instead as a relational process and as an aesthetic practice, that is a practice in which we understand others through our senses and our emotional engagement. The author has also underlined the role of emotions not only for the understanding of the fieldwork’s relations but also for the production of knowledge itself, arguing about the necessity for anthropologists to acknowledge emotions’ implications in their methodology (Spencer 2011). Yet, emotions are still left aside from methodological courses, confined to personal field-notes, treated with uncertainty, embarrassment or just silenced. This marginalisation is mainly due to the ideal of objectivity in scientific inquiry, which is based on an artificial distancing of the researcher from the “subject” studied. Actually, there no exist a neutral observer because there is not any possible detachment from her perspectives, moral commitments and bias or personal interests. Since emotions have enriched my ethnographic data with explanatory consistency, I attempted to commit myself to a style of writing capable to capitalize their epistemological value and to convey the fieldwork’s complex intertwining of emotions.

Chapters' description

In this dissertation, I first retrace the historical background of Portuguese child psychiatry by focusing on the figure of psychoanalyst João dos Santos, a pioneer in child psychiatry professional training and in child mental health practice (Chapter I). Here I explore the psychoanalytic approach to child psychopathology, its changing concepts, as well as the institutions, technologies, and events related to the developmental of Portuguese child psychiatry. This historical account reveals the conditions that enabled the identification and emergence of autism as a psychiatric condition in Portugal during the late 20th century and how autism was described and reported by mental health professionals of that time (Chapter II). This exploration contributes to a Portuguese local history of autism and illustrates the establishment and development of the first parent-led autism support association of the country.

After describing the process through which I gain access to the fieldwork, in Chapter III I explore parents' everyday experiences in living with and caring for their children with autism. By providing several ethnographic vignettes, I describe the reasons why parents decided to take part of autism support groups and the different ways in which they define themselves as activists. In this section, I also present the main Portuguese online support and advocacy group for parents of children with autism, *Os Amantes de Saturno*, and explore the main topics parents used to discuss within the virtual community. As a long-term condition, autism arouses several issues of social inclusion. In this respect, Chapter IV explores parent's advocacy struggles from inclusive school to social services for supporting the transition to adult life. In doing so, this chapter shows how advocacy practices, social struggles and political claims follow the temporal path of life, from childhood to adulthood. The aim, here, is also to acknowledge how parents' personal engagement in autism advocacy changed their subjectivity and made them active citizens engaged in raising public awareness about autism and disability issues, social justice and the inclusion of disabled people.

In Chapter V, I show the gendered division of caregiving labour in both their dimensions as bodily practices and socially expected tasks. In particular, I describe fathers' assertions of their care abilities and emotional relationships with their children in order to claim to their role as caregivers and their self-confidence. Later, I address mothers' affective discourses and practices of mothering as a political apparatus and focus on their role as main figures of autism advocacy movement in Portugal. Finally, in Chapter VI I explore the different purposes and use of technology for people with autism. I briefly describe how the Internet and its increasing

availability played a key role in the birth of the neurodiversity movement, by allowing the so-called “high-functioning” autistic people to speak for themselves and advocate for their own rights. Then, I address the use of mobile devices and augmentative and alternative communication (AAC) programs to improve social skills of children with so-called “low-functioning” autism. In the last chapter’s section, I critically interrogate the notion of “human” in order to explore citizenship issues when referring to those people with autism who present intellectual disability and cognitive impairments.

Chapter I

Autism and the Portuguese child psychiatry

In order to understand the emergence of autism as a distinct psychiatric disorder, anthropological studies explored the changing notions of child development and shed a light on the establishment of child psychiatry and psychology as disciplines in the early 20th century both in the UK (Evans 2013; Hollin 2014; Hollin and Pilnick 2015) and in the USA (Feinstein 2010; Silverman 2012). Anthropology literature also addressed the social construction of autism as a psychiatric label and its epistemological transformations as a result of biomedical technologies advancements and child psychiatry's changing paradigms (Bagatell 2010; Evans 2017; Eyal et al. 2010; Hacking 2010; Murray 2008; Nadesan 2005). These analyses show how, beyond its official history (Wing 1997; Wolff 2004), autism did not always follow the same path in all countries: as a living construct, it irremediably dived in the specific historical, social and political context of each country. So, in line with the above-cited site-specific studies, I envisaged to trace here the specific backgrounds of Portuguese child psychiatry that led to the emergence of the diagnosis of autism in the country. In order to explore this topic, my narrative thread will follow the chronological order of my own exploration of autism as it occurred during the fieldwork. Accordingly, I will first report my ethnographic encounter with a child psychiatrist working in one of the most relevant public early childhood psychiatric unit in Lisbon. His professional and personal history has a lot to say about the historical path of autism in Portugal and acquainted me about the psychoanalytic roots of Portuguese child psychiatry. I will secondly introduce the figure of psychiatrist João dos Santos, mentor of the first generation of Portuguese child psychiatrists and whose work and thinking were pioneering in the history of children's mental health in Portugal.

A plunge into the present

Since Leo Kanner first labelled and described autism in 1943, two main models have attempted to explain the emergence of autism and its supposed treatment. The psychogenic theory of autism - especially represented by Bettelheim work "The Empty Fortress" (1972) - has deeply contributed to the cruel and damaging portrayal of mothers of children with autism as refrigerator mothers. The cognitive model, instead, rejected this idea and conceived autism as a pervasive developmental disorder characterised by deficits in social behaviour and

communication and unusual, restricted and repetitive behaviours. Despite this latter view of autism is now accredited, the impact and authority of psychoanalysis in Portugal are still felt as deeply and parents' pronouncements on the psychoanalytic roots of autism's meaning have a lasting effect. I resolved thus to directly explore this topic with child psychiatrists working with autistic children in Lisbon. Accordingly, I eventually visited the *Dona Estefânia* Hospital, which has services in all paediatric specialities and represents a reference unit for maternal and childcare in the country since its establishment in 1860³. All child psychiatric facilities - namely a centre targeted at children up to 4 years old, one facility for school-aged children from 4 to 12 years old and the second one for adolescents aged from 13 to 18 years old - were located outside the hospital's area. After diverse attempts, I succeed to contact and meet only one child psychiatrist. With this encounter begins my own search for understanding the historical origins of the contemporary view of autism in Portugal.

Prelude

I well remember that day of April of 2015 when after lengthy e-mail negotiations I eventually succeeded to meet Dr. Lopes. He is the child psychiatrist who from 2000 is the chef of a Child Psychiatric Service (CPS) in Lisbon. The CPS opened in 1983 under the leadership of Dr. Maria José Gonçalves - mentor of Dr. Lopes - and of Dr. Antonio Coimbra de Matos, two of the most well-known psychoanalysts and child psychiatrists in Portugal. Since the beginning, this white prefabricated building is located in a northeast district on the outskirts of Lisbon⁴ in order to facilitate access to mental health services to families living in areas close to the capital. While walking along the main street, I stopped at the fire station and turning left I glimpsed the primary school, while on the right side at the end of the secondary streets I chanced upon the market, a meeting point of those who live there. Despite already feeling at ease within my fieldwork, I wrote some scribbled anxious notes in my field journal. I was overthinking the meeting and worried that the doctor would have been on the defensive and he would not eventually answer my questions.

³ *Dona Estefânia* Hospital was built at the behest of the then king of Portugal *Don Pedro V* to honour his late wife's will. The story tells that while visiting the *São José* Hospital, the queen *Dona Estefânia* get shocked about children's neglect and hospital wards' conditions. So, she offered her wedding dowry to build an independent paediatric hospital.

⁴ This district was built around the 1930s at Salazar's behest for housing purposes. It is characterized by twin villas separated by green areas functioning as leisure spots for the residents. Commonly depicted as a dormitory district, its symmetry captured my attention because of its own topography made by three main arteries creating likewise points of convergence - a church, a school and a market.

When I eventually arrived at CPS, four female professionals - some of them wearing the white coat - were taking advantage of a break to smoke a cigarette at the threshold of the gate. After passing the front door, I asked a woman who was sitting at the desk in the right corner to tell Dr. Lopes about my arrival. Apparently, I had to wait about 20 minutes because of a medical consultation that was lasting more than the expected. I gained the exit and took the opportunity to write down these few descriptive notes I am now reporting about the site and the people I met. The same woman then informed me that the doctor's visit would last more and invited me to wait in the waiting room together with two other women and their toddlers. Here, one of the mothers started to talk with me while her four-years-old girl was playing with a huge tipper toy truck trying to fill its rear basket with different plastic fruits. Her toddler is a so-called "non-verbal child" with autism and according to the mother thanks to the CPS professional team she recently learned to eat soup on her own: "it may seem like nothing, but to me it is a lot, you already know that soup is a very common meal here in Portugal, don't you? She eats by herself at school now, she has progressed a lot! (...) But she doesn't say anything, nothing, nothing at all!" The other woman silently looked at us with her half-closed eyes that made her face look tired. Because of the early age of her son, who in the meantime was quietly nibbling on his closed fist, I assumed that she was waiting for her son's first diagnostic consultation. This pretentious thought made me feel deeply awkward. The anthropologist that I was performing was whispering me that this circumstance may turned into an invaluable moment of participant observation. Instead, I felt so out of place and uncomfortable while observing how emotionally different we were experiencing our own "waiting room" that I pretended to check the time on the mobile phone.

Dr. Lopes is an expert on early identification and interventions for ASDs. Among different therapeutic approaches such as psychotherapy and speech therapy, the CPS's medical team employs an intensive method targeted for children aged less than 4 years old called Floortime. This latter one presupposes the cooperation between the medical team, the kindergarten's teachers and child's parents. For instance, child psychiatrists and therapists help the family to choose the optimal therapeutic path for the child and offer their support over the years. The CPS is also equipped with a sensory integration occupational therapy room, which provides controlled sensory experiences in accordance with child's specific needs, helping the child to process sensory messages if she is "under-sensitive" or to filter overstimulation if she feels "sensory overloaded". Heightened sensitivity is indeed one trait of autistic people who tend to avoid excessive stimulation and ordinarily turn away from sound, touch, bold colourful

patterns, strong tastes and aromas, and interpersonal contact (Pfeiffer et al. 2011). Dr. Lopes' secretary told me that I would have been the next one to "see" the doctor and after more or less one-hour wait I eventually entered his office.

The CPS team

Dr. Lopes sat down at his desk full of sheets and folders. I took my seat in front of him by avoiding stepping on a toy lying on the floor. Behind me, two chairs circumscribed a space with a few toys scattered on a soft rug made by the famous multi-colour square puzzle blocks. The office, in fact, works also as a room for early detection and diagnosis: together with a multidisciplinary team the doctor carries out over several sessions a diagnostic evaluation, outlines a child's profile in terms of her social interaction, communication, behaviour and sensory integration and finally elaborates an intervention plan adjusted to child's specific characteristics and needs. This service, Dr. Lopes explained, "can really make a difference and positively affect autism's evolution". Also, the medical team usually arranges two meetings per week with parents: a so-called "case orientation meeting" with the purpose of discussing a patient's case in order to plan further therapeutic decisions and an "interaction meeting" where the team examines therapists and psychologist's personal notes about the child as well as a video of her interactions recorded during consultations up to the age of 2. Consultations are indeed particularly relevant for Dr. Lopes' medical team working according to the Floortime approach as it encourages parents to engage children literally at their level, by getting on the floor to play. During these sessions, parents are also invited to temporarily leave the consultation room while doctors and therapists keep on observing the child playing in order to see whether she is feeling calm or distress or if she is looking to be comforted by someone. Then parents are let come in and the team observes if the child feels comforted by their presence, as well as asks parents how they play with their child at home. This process represents a very intense training for the team as elucidated by Dr. Lopes' words:

"the team learns to observe (...) when working with babies it's fundamental to observe where they are looking, their distance from people, their movements, how they react to people, to pay attention to their reactivity to sensory stimuli, our work is on the floor with them, next to them...because since words come much later we approach them, we communicate with our movements, with the eyes, with the touch, with the play's rhythm, with our emotional bonds and this is very demanding from a personal point of view because we actually identify ourselves with the children against the parents! Parents are the worst! And this must be resisted in order

to help both parents and children...this doesn't mean that there are not horrible parents and very difficult children but only by learning to observe we can be able to do this work".

Confused noise coming from the outside indicated that a Floortime therapy session has ended, and despite I was distracted by the noise of probably some toys thrown on the ground and of some festive applause, I eventually asked the doctor to deepen his thought about the emotional difficulties of working with so young autistic children:

"I always ask the therapist: "how did you feel?" (...) because the emotional impact of the observer is part of the diagnostic process and usually people try to defend themselves and say, "I think that the mother is..." and me "No, No, tell me how did you feel!" You know we too feel very sad and restless (...) the child has a deep impact on us (...) paediatricians spend their lives listening to children cry but then they learn how to not be affected. This is heavy and difficult! the child I saw before you...in two years she did not get so much progress, it's really sad!"

The Floortime therapy and the specific diagnostic procedure described by the doctor refer to a method of intervention for autism called DIR (Developmental, Individual Difference, Relationship-based model) introduced in the USA during the late 1980s by psychoanalyst and child psychiatrist Stanley Greenspan and clinical psychologist Serena Wieder (Wieder and Greenspan 2001). Dr. Lopes closely endorsed the DIR method since the beginning by participating in early intervention teams in Washington together with Dr. Greenspan himself and eventually become a pioneer in Portugal. DIR model focuses on child's individual characteristics and it is employed worldwide as an alternative to behavioural models, such as the ABA (applied behavioural analysis) developed by Ole Ivar Lovaas. This latter aims to teach autistic children to acquire language and socially significant behaviours (such as reading and adaptive living skill) through imitation, repetition and positive reinforcement. Dr. Lopes, as well as some of the parents I encountered, emphasizes how intensive training and behavioural conditioning make the ABA approach alike to a mere "stimulus-response" technique that does not provide autistic children with long-term and context-sensitive skills but rigid and repetitive behaviours. On the contrary, DIR/Floortime approach relies on the idea that children and especially those with developmental challenges like autism need to develop adaptable behaviours as emotional experiences and capabilities - which drive child's developmental path and are critical for her full participation in life and connection with others - rely on flexibility. That's why Floortime is usually referred to as "ABA Detox". After almost twenty years of

experience of Floortime, Dr. Lopes reiterated his criticism against ABA therapy, which he firmly defines as “mere training, as you do with animals”. During our conversation, he also stressed how unlike ABA, Floortime is a relational-based and child-leading approach as it takes place on the floor with an adult (the parent and/or the therapist) following child’s own interests towards toys, objects, or actions. As a result, while behavioural approaches such as ABA suggest parents correct their children alleged non-functional or non-social behaviours and to ignore their “bad” actions such as frustration, anxiety or anger, the DIR/Floortime approach creates an engaging context in which the caregiver responds to child’s demands and challenges⁵.

After they both coincidentally died in 2010, Lovaas and Greenspan leave behind them a strong controversy together with post-mortem tributes to their respective works. The debate around which is the best effective autism’s early therapeutic intervention is still alive. On one hand, applied behavioural methods promise to have an impact on autism prognosis or outlook by reducing the child’s “inappropriate” behaviour and increasing her communication and learning skills, as well as her appropriate social behaviour. On the other hand, although Floortime appears a plausible method of treating ASD, Greenspan’s assumed typical development stages are not always the same for all people and thus do not necessarily indicate an appropriate pattern for treatment of all autistic children (Mercer 2015:9). But Dr Lopes’ biggest concern is that Floortime is still referred to as a “last vestige of psychoanalysis”. According to his words, Floortime is a relational model that “still drinks from the sources of psychoanalysis [even if] it no longer blames the mother for their children’s autism”. Indeed, even if Greenspan abandoned “those unfounded ideas about mothers’ role in autism appearance” - that is, refrigerator mother hypothesis - his therapeutic model focuses on child’s relational attitudes with others, primarily parents.

The cold war between behavioural and relational approaches to autism, so deeply embodied in Dr. Lopes’ words, dates back to an old-aged controversy. When behavioural therapies emerged during the 1960s, the idea of subjecting children with autism to “operant conditioning” (a learning process through which the strength of a behaviour is modified by reward or punishment) conflicted with the then prevailing assumption that autism was a form of emotional

⁵ During a Floortime session, the child is usually leading the interaction, while an adult (a parent, a teacher, a therapist or the child psychiatrist) is allowed to creatively change or adapt some of the child’s activities in order to get her attention.

withdrawal. As a matter of fact, in his landmark paper “Autistic Disturbances of Affective Contact” Leo Kanner (1943) - the first psychiatrist to clearly describe autism in 1943⁶ - interpreted atypical behaviour of his young patients as a product of a disturbed familiar or parental environment. As predicted from the article’s title, Kanner understood autism as an affective disturbance: an “innate inability to form the usual, biologically provided affective contact with people” (idem:250). From its very beginning, then, autism aetiology questioned family relationships and parents’ ability to emotionally connect with their child. It was especially the mother who was charged with the responsibility for her child’s condition (Caplan 1998; Waltz 2015). Bruno Bettelheim (1972) argued that autistic child’s desire for aloneness indicated that she was protecting himself from parental rejection. He was thus in need of an accepting therapist able to draw him out from his “empty fortress”. Working during the post-World War II, both these psychiatrists were strongly influenced by psychoanalysis, which located the origin of infantile psychopathologies within the familiar environment. Psychiatry, and in particular child psychiatry, was also trying to gain scientific recognition and to construct a strong theoretical explanation of infantile “madness” (Shorter 1997:5). The assumption according to which the autistic child was an emotionally wounded child who chosen to withdraw remains dominant throughout the 1960s, ‘70s and even ‘80s (Silverman 2012; Wolff 2004). No wonder then that even if this explanation began to be discredited during the ‘80s - when autism eventually began to be understood as a developmental disorder of likely neurological or genetic origins - therapies and treatments were still largely influenced by psychoanalysis thinking and relational techniques.

As Dr. Lopes mentioned, Greenspan - who was working exactly during the ‘80s - refused the parent-bashing aetiology and greeted instead some of the then-newly neurobiology and neuroplasticity’s deductions. If autistic children have difficulties to engage in long reciprocal affective interactions, as well as to miss the ability to motor planning, for biological reasons, it is only within a context of an enjoyable affect-driven flow of interactions that their brain’s properties could be ultimately influenced (Greenspan 2001). Children with autism, thus, could learn speech, social skills, creative and abstract thinking through an “Affect-Based Language

⁶Austrian psychiatrist Kanner immigrated to the USA in 1924. Here, he started working as head of Child Psychiatry Department at the Johns Hopkins University. Kanner article concerned his clinical work with 11 children described as highly intelligent but with a strong desire for aloneness, severe difficulties in social interactions, an obsessive insistence on persistent sameness and difficulties in changing routines. as well as auditory hypersensitivity and echolalia (the automatic repetition of another person’s words). He referred to their condition as “early infantile autism”.

Curriculum” (Greenspan and Lewis 2005), a methodology employing affect and engagement in reciprocal interactions. As a result, Greenspan encouraged parents to appreciate the role of affective exchanges and to engage with their child in a non-directive manner, sitting beside her and acknowledging and joining her ways of interacting. The DIR/Floortime model represented de facto a way to operationalize the role of affectivity and emotions during the therapeutic intervention process: its three key components - capacity for intimacy, an ability to communicate expressively, and the capacity for meaningful speech - always require indeed an emotional engagement (Wieder and Greenspan 2001). Difficulties in the emotional domain have been always considered a feature of autism. For instance, the Sensory Integration therapy room, which I mentioned earlier, also relies on the assumption that children with autism avoid human contact as they feel emotionally overwhelmed (Greenspan and Wieder 2003:14). The flood of both sensory and emotional world is indeed described in autism literature and in autistic people’s autobiographies (Grandin 1995; Prince-Hughes 2004; Sacks 1995; Williams 2000; Zelan 2003).

Floortime therapy help parents and therapists persuading children to join the people world and to feel understood and protected, finally argued Dr. Lopes. Within this networked context, children can potentially achieve flexible and adaptable behaviours, as well as skills to relate and communicate. It seemed then clear to me how the child-caregiver relationship was at the heart of the DIR method and that family and its own interactional patterns still represent the elected context able to deeply affect child’s neurological plasticity. For instance, as components that help children processing external information, parents’ proximity, their voice and touch constitute some of the core elements used during a Floortime session. On this topic, recent studies argued that hearing mother’s voice can activate multiple brain systems, such as those related to emotion and face-processing (Grossmann 2010), can provide a neural fingerprint of child’s future social communication abilities (Abrams et al. 2016), as well as raise oxytocin (the “love hormone”) level (Seltzer, Ziegler, and Pollak 2010). Autism-related literature often depicts parents as close and active agents in child therapy (Ozonoff, Dawson, and McPartland 2002; Siegel 1996; Zelan 2003). Nevertheless, it is unequivocal that these studies remarkably portray mothers as preeminent figures of child’s social and emotional development.

After my conversation with Dr. Lopes, I acknowledged the relevance of looking at the influence that both theoretical and technical backgrounds have in his professional practice and particular understanding and interpretation of autism. Diagnostic and therapeutic methods do always

represent indeed powerful agents of the historical construction of a psychiatric disorder and autism is not an exception. The theoretical and practical devices used by Dr. Lopes fabricate his choices, from the therapies he practises and prescribes to the way he describes autism. In this regard, he often highlighted how the diagnosis method deeply influences how parents construct their own expectation regarding their child's autism prognosis.

The epistemological path of a disorder.

Psychiatric classifications virtually conform to a specific epistemological paradigm, that is a framework of thought patterns, theories, research and diagnostic methods, care practices and treatment procedures performed by the scientific community. By giving a name to a person's symptoms⁷, psychiatry is able to circumscribe a "condition" and portray its presumable complications and prognosis, that is doctor's judgment of the likely or expected development of the condition. Hacking (1991, 2006) has shown how clinical classifications affect the people labelled and how these, in turn, change the classifications. This positive mutual relation shows that a diagnosis is a socio-historical contingency, responding to the need of describing, classifying and managing a disorder (or a disease). Over time, many diagnoses have changed according to the different theoretical paradigms and technical procedures that biomedicine has produced and passed through. Psychiatric labels thus virtually described always "mutable" conditions. For instance, what was once designed as melancholy or profound sadness it is now classified as depression, a mood disorder mainly treated with counselling and drugs therapies. This change is usually traced back to antidepressants development and the consolidation of biological explanations of depression since the late 1950s (Lawlor 2012). Similarly, the term hysteria (from the Greek *hysteron*, uterus) once used to label supposed feminine "pantomimic" or "theatrical" behaviours it is no longer considered by the DSM as a distinct psychiatric disorder but instead a somatic symptom of schizophrenia or bipolar disorder (Allison and Roberts 1994; Ávila and Terra 2012; Micale 2000). Also, the introduction of improved diagnostic techniques since the early 20th century led to a greater understanding of psychological conditions, so that before the introduction of electroencephalography hysteria was frequently confused with epilepsy (Hacking 1998:2). So, changes in theoretical paradigms and the development of new diagnostic techniques fabricated new interpretative frameworks.

⁷ The identification of the nature and causes of a symptom (or a series of symptoms) is essential to produce a psychiatric diagnosis. For this purpose, the psychiatrist uses a conventional set of diagnostic methods, which can be "instrumental" (namely equipment or special devices) and "clinical" (when the diagnosis is based on the direct observation of patient's symptoms and behaviours).

This mutual and interactive process explains why a diagnosis could have different meanings or even considers a different set of symptoms under the same label during the course of its history.

This issue is quite relevant with respect to autism. Indeed, despite autism has acquired a broader public, political, and biomedical prominence only from the 1980s, it already since its first appearance in the 1940s that its understanding and social representation have continuously changed (Hacking 2010; Mintz 2017; Murray 2008; Silverman 2012; Wolff 2004) and (Hollin 2014:99; Hollin and Pilnick 2015). Every one of its historical explanations has its own aetiology (affective-relational, neurobiological, genetic), its hypothetical pathogenesis (that is, the identification of likely mechanisms - such as mother-child relationship, vaccine, neurophysiology, or even food allergies - behind its appearance), as well as its related different therapeutic models. Autism has, therefore, embodied within its own changing framework of interpretation different biomedical practices and theories, as well as cultural and moral values. As Nadesan (2005) argued, we can say that

“the idea of autism is socially constructed (...) to point to the social conditions of possibility for the naming of autism as a distinct disorder and to the social conditions of possibility for our methods of interpreting the disorder, representing it, remediating it, and even for performing it” (idem:2)

Autism’s appearance also followed the development of different professional profiles such as psychiatrists, psychologists, social workers and special teachers, many of which either emerged or begin to be professionalized in the early 20th century. There is no doubt that before this date, people have probably displayed symptoms we now group and define as autism. For instance, in *Autism in History: The Case of Hugh Blair of Borgue* (Houston and Frith 2000), the authors claim that the “syndrome” we call today autism already existed in 18th century Britain and Europe. Nevertheless, autism could not have been considered as a distinct disorder before the mid-20th century. More precisely, Nadesan infers that “within the scientific taxonomies, medical nosologies, and medical practices of the 19th century” autism was “unthinkable” (Nadesan 2005:3) and also that it “could not have emerged in the 19th century as a diagnostic category because the paediatric experts - Leo Kanner and Hans Asperger - who produced it were a 20th-century phenomenon” (idem:53).

The term autism - whose etymology comes from the Greek αὐτός (autos) meaning self - was first reported in 1908 by a Swiss psychiatrist, Eugen Bleuler who used it to describe a symptom

of a schizophrenic patient who withdrawn into his own world, showing a morbid self-admiration. Despite this precedent, Leo Kanner and Hans Asperger are the pioneers of autism's modern meaning. While the first derived its notion from Bleuler description of schizophrenia, the second "re-contextualized [Bleuler] concept within the framework of a personality disorder" (idem:5). Both psychiatrists wrote about their autistic children patients during the 1940s, but they did not know about each other's work as Asperger's article was translated from German into English only in 1991 (Asperger 1991) by child psychologist Uta Frith. As I mentioned before, during the early-20th century the understanding of autism was strongly influenced by the psychoanalytic paradigm that ascribed the origin of childhood psychopathology to family's relationships and interpersonal dynamics.

The powerful fragmentary nature of autism

"Autism has to do with human relations. Even if I do use the term autism, I'm talking about disorders of relationship and communication because in this way I increase parents' expectations and I provide an explanatory model that is not merely grounded in [the idea of] functioning (...) from the clinical point of view this means a lot because this little difference with DSM's classification makes all the difference in the way autism is treated and affects parents in a much more positive way, their expectations could be influenced by just removing the word autism!" (from Dr. Lopes' interview)

In line with his vocational education, Dr. Lopes autism classification system is consistent with a diagnostic manual called DC: 0-3 (Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood) commonly knew as "ZERO-TO-THREE", rather than with the conventional DSM approach. The DC: 0-3 diagnostic categories reflect the consensus of a multidisciplinary group of experts and turned out to be another invention chaired by of Greenspan. Its 2005 revised version (the 1st edition dates back to 1994) responds to three main principles: 1) that children's psychological functioning unfolds in a relational context, 2) that individual differences play a major role in how children experience and process events, and 3) that family's cultural context is relevant for the understanding of child's development. According to the ZERO-TO-THREE approach, the DSM "autism spectrum disorders" corresponds to the category of Disorders of Relating and Communicating. Dr. Lopes, indeed, considers the DSM taxonomy inappropriate as it keeps using the word "autism" and comprising it within the extensive category of developmental disorders. On the

contrary, the DC: 0-3 classification positively influences diagnosis' perception by cutting off the word autism and by drawing more attention to the dynamic aspects of the condition - such as relatedness, communication, emotions, and sensory processing - rather than to its chronic feature (Caldeira da Silva et al. 2003:32). This idea of autism as a dynamic rather than as a fixed condition (Greenspan and Wieder 1997) increases the hope of those parents who struggle with the idea of autism as a chronic and lifelong disorder.

The lack of a univocal classification of autism resides perhaps in classification systems' ambitious pretention to provide a description unifying genetic, biochemical, neurophysiological and neuroimaging findings and to identify a specific category with a unique history, prognosis and therapy. Classification systems also claim to be coherent and easy to use in clinical settings, especially with infants and toddlers (Cantwell 1996; Clark, Watson, and Reynolds 1995; Scott 2002). International diagnostic systems have received different critics with respect to their supposed application to the infantile population⁸. With regard to autism, for instance, the DSM III (American Psychiatric Association 1980) included for the first time autistic disorder and Asperger's disorder within the Pervasive Developmental Disorders (PDD) category, a label aimed at merging those children showing persistent non-conforming behaviours in diverse areas of their development. The PDD category, as well as the Pervasive Developmental Disorders-Not Otherwise Specified (PDD-NOS) category - a revised notion introduced in the DSM IV-TR (American Psychiatric Association 2000) that unified all "autistic-like" syndromes previously described - attracting both much criticism (Bildt et al. 2004; Borden and Ollendick 1994; Buitelaar et al. 1999; Gadow et al. 2005; Witwer and Lecavalier 2008). Literature systematically evaluates the legitimacy and utility of autism's labelling, still after the latest and fifth edition of the DSM that recognizes the "spectrum" nature of autism by subsuming and replacing all the previous label into a unique umbrella term ASDs, Autism Spectrum Disorders (Brukner-Wertman, Laor, and Golan 2016; Lai et al. 2013; Leventhal-Belfer 2013; Wing, Gould, and Gillberg 2011). The biomedical term ASDs is thus the (temporary) present-day label used to name a condition continually shaped by changing theoretical and clinical models. It presumably embraces a continuum of autistic traits, from the "classical" autism described by Kanner to former Asperger's syndrome and autistic-like traits in intellectual disability (ID),

⁸ Several comparative studies employed different classification systems on the same sample of patients to discuss the validity of autism diagnostic criteria (Postert et al. 2009; Waterhouse et al. 1996). Despite some homogeneity (Chiappedi et al. 2010), a unique and inclusive label of autism seems to be missed. In addition to this, some autism's specialists suggested to employ the term "condition" (Baron-Cohen, Scott, et al. 2009) instead of "disorder", as this latter implies that something in autism should be "broken" (Lai et al. 2013).

once called mental retardation. Eventually, as I described earlier, Dr. Lopes interpretation of autism as a relational disorder reveals a hermeneutic framework that embodied psychoanalytic thinking, as well as psychodynamic philosophy.

The political weight of autism lexicon

“For me it’s kind of obvious but people still forget [that the appellative] “autistic child” is incorrect because the disorder does not define the person. It’s a political matter. There are adult people with mild autism who define themselves as autistics but this may be very difficult for parents’ expectation when they are dealing with young children with severe forms of autism! Also, here in Portugal, people use the term autistic as an insult...the Assembly of the Republic has tried to make a law and even Autism-Europe was asked to intervene, can you imagine that? (...) It’s dramatic how [a word] can impact the way children are treated by common people who don’t care too much...people need labels, they need a lot! You know why? Because then you have children with SEN [with Special Educational Needs], which means that you will have the SEN children on one side, and all others so-called normal children on the other side! I fight a lot against this, there are no children who are inherently autistic! Write down that this is important to me!” (extract from Dr. Lopes’ interview)

Dr. Lopes’ emphasis on the political reason of using the DC:0-3 terminology shows, to my view, that the ways in which autism is described have a huge influence on parents’ and common people. At this regard, if the language we use to describe people says a lot about what we think about them, then the common use of psychiatric labels to describe people within the public space assume a particular relevance. As they isolate and recognise only some aspects of an individual as her identity-making features, psychiatric labels may also contribute to constructing narrow and harmful stereotypes or even false assumptions about people’s individuality. Media and society at large magnify these biomedical constructs by sharing them into the public domain, shaping ways of “seeing” autism that reinforce value judgments. For instance, autism is still wrongly thought just as an infantile condition and people with autism are generally described as not emotional, self-interested people unable to share their world.

The debate around the terminology to be used to describe and address people with autism does represent an issue for mental health professionals and also society at large. There is not, indeed, a single way of describing people diagnosed with ASD universally accepted or preferred by biomedical scientists, autism’s community and broader society (Kapp et al. 2013; Kenny et al.

2015; Lowery 2015). As Dr. Lopes interview shows, the main controversy regards whether one should say he or she “has autism” or he or she “is autistic”. During my fieldwork, some parents use a so-called “person-first” language when speaking about their child, putting - as they said - the person before the disorder. In this case, by saying “this is André, my son with autism” or “my son André has autism” instead of “André is autistic”, you are not defining André by his medical condition. These parents generally view the term autistic as alienating insofar as it may connote children with autism as different kinds of human beings (Bagatell 2007; Jaarsma and Welin 2012). Conversely, so-called Asperger people and neurodiversity activists, as well as parents of children diagnosed with former Asperger or “high-functioning autism”, dissent from this view. A person-first language, they argue, suggests that autism is something external that happens to a child, implying the idea that a child with autism needs to be “fixed” (Brown 2011). Instead, it is not possible to separate the autism from the person as it is not a disease nor something to be cured (Sinclair 2013). Accordingly, the term “autistic(s)” is used by those people who see autism as an integral aspect of who they are, rather than an external accident. While autistics could anyhow need help to overcome communication and sensory challenges, they do not need fixing. Autism, according to this view, is a way a way of being and experiencing the world, a confident part of people personality that makes them who they are and affects the whole way they think and process the world (Baker 2006; Runswick-Cole 2014).

As people, we embrace different kinds of identity classifications and we create (and reiterate) some assumptions about people insofar as this helps us to quickly make sense of the world around us. Many of these social constructs are often based on people’s physical appearance or observable and quite decipherable behaviours, which are the most visible characteristics of an individual’s self⁹. This means that other equally important aspects - usually less visible as the former ones - remain underrated. “It’s not in the face, but it does exist” became one of the most famous slogans against the apparent invisibility of intellectual disabilities, like ASDs. At this regard, autism’s visibility - be it thought as a cognitive disability, a mental disorder or a different way of being - lies in people’s behaviours and ways of reading and perceiving the external world. These aspects, however, do not necessarily nor entirely fit in with a supposed univocal description of autism. Indeed, a label forces us to narrow the richness of someone’s phenomenological world in order to comply. Parents’ descriptions of their children’s ways of “having autism” or “being autistic”, as well as my own experiences of interactions with them,

⁹ For instance, the exposure and visibility of physical traits are what people generally use to develop a language around race and gender and to construct a vocabulary narrowly based on skin tone or sex characteristics.

showed me the impossibility to encompass the phenomenological polymorphism of autism into a pre-established label. In other words, by behaving in her own terms every child actually resists to any virtually univocal idea of autism. So, how it is possible to acknowledge the manifold differences between people who despite being defined by the same psychiatric they are experiencing completely different autisms? The ability of anthropological writing to describe people in a way the closest as possible to the living experience solved in part my will of not limiting the open-endedness of autism condition with the use of a fixed label. In addition, when necessary I usually adopted the expression - namely, “child with autism” or “autistic child” - that each parent felt most comfortable with when referring to their children. I preferred to adapt to parents’ terminology also to acknowledge their own way of describing autism and of thinking about their children. Yet, sometimes parents employed the Portuguese word *autista* (autistic) to refer to so-called high-functioning autistics or former Asperger children, as well as to a child with a severe form of autism. Fieldwork represented, in this sense, a fruitful opportunity not only to face my own stereotypes but also to weigh up my own ethical issues on labelling. For instance, I learned to avoid using the term autistic as an adjective for someone who was shy or introverted and to admonish those friends who improperly used it, such as when they ironically address me as autistic to complain about my absence during the writing of my thesis.

Taking into consideration my own fieldwork, many parents denounced the improper or harmful use of psychiatric labels. The amplitude of this cultural, social and political change depends on society’ will to challenge its thought pattern. Since autism’s lexicon always embodies a hermeneutic - namely, the way I give meaning and interpret autism - Dr. Lopes consideration about the political relevance of autism terminology pointed out a complex issue to deal with. Moreover, his concern about the public use of autism’s terminology shows how social interactions may reinforce but also challenge the stereotyped and disrespectful use of psychiatric label and eventually contribute to weakening their validity.

About the changing nature of autism (spectrum disorders)

During the 1990s, according to Dr. Lopes, several Portuguese paediatricians and child psychologists questioned the idea of a supposed relational nature of autism in order to eventually introduce and adopt cognitive-behavioural therapies. The opportunity of new autism treatments contributed to the emergence of the first child mental healthcare services and child development centres in the private sector. While recalling this occurrence, which in his opinion marked a radical change in autism healthcare in Portugal and still affects the authority of child

psychiatry practitioners working in the public sector, Dr. Lopes' voice betrayed a mix of regret and pride. Whilst he accused part of his colleagues of having been "blinded by the new market of autism treatments", he also blamed the first generation of child psychiatrists of that time of having frightened families with their psychogenic explanations and of not having provided alternative therapeutic options. Also, as psychotherapy for autism was charged with lacking scientific objectivity, child psychiatrists trained in psychoanalysis felt compelled to regain legitimacy within the medical community and towards parents and society at large.

In an attempt of detaching herself from its psychoanalytic roots, Portuguese child psychiatry progressively embraced cognitive theories of autism that began to appear in the mid-80s and consolidated during the 1990s. Cognitive explanation of autism "proposed that some of the core elements of autism might arise from a primary cognitive deficit. In doing so, the theory imposed a developmental psychological perspective on research and became hugely influential for both researchers and practitioners" (Rajendran and Mitchell 2007:225–26). As shown by Hande et al. (2016) in the United States, in last decades autism gave rise to lucrative opportunities for financial investment. According to the authors, parents contributed in developing private therapeutic centres, "playing an increasingly important role in marketing new treatments and creating a for-profit treatment, research, and educational initiatives" (idem:82). Notably, since autism self-advocacy communities and family associations increasingly criticized psychogenic theories, the psychotherapeutic method gradually lost its prominence. Latest findings in autism neuro-physiology and genetics - despite still looking for definitive evidence and consensus - have nowadays deprived psychoanalysis of its authority as a therapeutic dispositive. Yet, the controversy around psychoanalysis efficacy in treating autism represents one of the aspects of a general crisis of its role within child mental health sector.

The private child mental health sector also brought, according to Dr. Lopes, a singular increase of Asperger's syndrome diagnoses in the country. While a greater attention to autism spectrum disorders and disability issue was spreading in the country, this "epidemic" shows for him the interest of private child mental-health facilities to grab most ASD-specific treatments:

"A lot of neuro-psychiatrists, whose names I cannot divulge for ethical reasons, started to diagnose Asperger's syndrome for economic reasons, to lure families, they abused of their position in order to lure customers to their private centre...Asperger syndrome is a milder form of autism spectrum and so parents accept it more easily!"

In 2012, according to Piedade Líbano Monteiro - president of the Portuguese Asperger's Syndrome Association (APSA) and mother of a 23-year-old boy with Asperger syndrome - there are more than 40,000 children and teenagers diagnosed with Asperger in Portugal. This mere statistical data cannot confirm Dr. Lopes' claim about Portugal as one of the countries with the highest rates of Asperger syndrome in the world. The first and only epidemiological survey carried out in Portugal in 1999-2000 revealed an estimated prevalence of autism of 0.92 per thousand children in continental Portugal and 1.56 per thousand in the Acores islands (Oliveira et al. 2007)¹⁰. Although the lack of further epidemiological data on autism incidence in Portugal, the Portuguese Federation of Autism (FPDA) estimates that about 2.300 families have one or more children or young people with autism. Accordingly, the theme of the 2013 Autism Awareness Day (2nd April) in Portugal was "Autism: there are more people than we think".

Without denying the role he ascribed to the private sector, the rate increase of autism-related disorders over the past several decades is mainly due to other main factors, namely to a broadening of ASDs diagnostic criteria, to better diagnostic screening and to an increasing awareness of parents in identifying autism-specific behaviours. As mentioned before, understanding of autism has changed over the time leading to the formulation of new diagnostic criteria. The first report on autism prevalence in Europe (EC 2005), for instance, indicates a dramatic rise in autism prevalence after the introduction of the DSM-IV criteria (1994). In particular, the inclusion within the umbrella diagnosis of "autism spectrum disorders" of different autism-related conditions before considered as separate disorders (such as Asperger syndrome, Rett's Disorder, Childhood Disintegrative Disorder, Pervasive Developmental Disorders) may account for a prevalence rise from 16 cases to 63 cases per 10000 people (EC 2005:4). Compared to the wider DSM-IV criteria, Kanner former criteria did not specify an average age of diagnosis (now fixed before the 3 years of age) and took into account only two main symptoms, namely a profound lack of affective contact and repetitive/ritualistic behaviours, leading to lower prevalence rates. Autism prevalence rate represents, still, a quite unclear data as it relies on the variability of the methods of case finding and analysis. Even with the same system of classification, diagnosis rate may differ because of the way professionals apply the criteria (idem:5-6). Furthermore, the scarcity of national epidemiological studies

¹⁰ The study involved 332 808 children born from 1990 to 1992 who were attending the 1st cycle of basic education. About the half of the diagnosed children were enrolled in special education schools.

makes difficult to estimate ASD cases in each European country, as well as to carry out comparative studies (EU 2015)¹¹.

Besides the impact of conceptual changes (i.e. the development of a wider autistic spectrum), autism rise represents the historical consequence of an increased surveillance on childhood mental health (Eyal et al. 2010). A greater knowledge among parents and professionals dealing with developmental disorders of childhood and the growth of specialist services have strongly contributed rising prevalence of autisms disorders (Wing and Potter 2002). Autism organizations' fights for a greater recognition of intellectual disability and demands for better services have also contributed raising autism awareness. Another plausible reason for autism prevalence rise is the advance of early diagnosis techniques in both public and private facilities, which allows diagnosing children in early childhood (Nadesan 2005:3). Nowadays, official US rate appraises that autism prevalence increased from 1 in 150 children in 2000 to 1 in 68 children in 2012 (Centers for Disease Control and Prevention 2016). The rising trend has, yet, a crucial political relevance as it fabricates the idea of autism as an epidemic¹², that is as if more and more children were born with the disorder.

As Dr. Lopes vehemently emphasized the harmful role of private mental health services and developmental centres, I further asked him about their current impact. Alike the USA and other European countries, also in Portugal the so-called the new market of autism treatments has deeply changed child psychiatry and its practices of care. The spread of behavioural and cognitive therapies favoured the advent of private assessment and treatment centres, where a team of professionals provide interventions for children with SEN. In Dr. Lopes' opinion, autism is still a very desirable object of economic interest for neuro-paediatricians:

“they make a prescription! without taking into account the child and her relational history, this doesn't matter for them! the same happened with attention deficit disorder...there is a symptom, then you give a drug and that's it! and again this happened because child psychiatrists are still associated with psychoanalysis...unfortunately, we frightened families and pushed them away”

¹¹In 2015 the European Commission launched the project ASDEU (Autism Spectrum Disorders in the European Union - <http://asdeu.eu>) in order to establish a prevalence estimation of autism disorders and of its different subtypes. The project also aims to investigate autism-related social and economic costs and design a protocol for autism early detection. Different European partners have already met for a Mid-Programme Technical Workshop in Edinburgh in September 2016 to share preliminary data.

¹² While an epidemic is a spike of *occurrence* of new cases, that is an increase in the incidence rate, an increased *prevalence* rate represents the percentage of the population affected by a condition.

Once again, he was revealing other important aspects of Portuguese medical establishment's approach to autism. On one hand, the increased use of psychoactive drugs, especially Ritalin a stimulant also used to treat Attention Deficit and Hyperactivity Disorder. On the other hand, the regret I previously read in his words eventually referred to the burden of psychoanalysis on Portuguese first generation of child psychiatrists. The CPS itself, indeed, is the last heir of that psychoanalytic thinking, despite Dr. Lopes describes himself as a "marginal psychoanalyst":

"I became a child psychiatrist when the Child Mental Health Centre was completely led by psychoanalysis, a very orthodox and French psychoanalysis...we were supervised by French psychoanalysts as soon as the discipline was launched in Portugal by Dr. João dos Santos (...) You know I never wanted to do formal psychoanalytic training because I didn't like the method at the time...we didn't blame the mothers but the idea of guilt was always there and this was very clear in the way autism was understood...the therapies I learned aimed at rebuilding something that was seen as having gone wrong or destroyed (...) we use *maternage* technique because João dos Santos thought that the primary, maternal relationship had to be rebuilt, it was very abusive thing to do! (...) all this had very negative consequences for the mothers and very serious consequences also for child psychiatry! We were cut off from the autism market, we ended up at the margins and lost the opportunity of helping children with autism. Even today we suffer from it, there are remnants of this mentality in today child psychiatry in Portugal".

I recalled, for instance, how some mothers I encountered complained of being still considered responsible for their child's autism. Parental guilt is not such an out-dated feeling when talking about autism. I thus steered our conversation towards the psychoanalytic roots of child psychiatry in Portugal. I was interested in exploring how parents and professionals still interlaced autism with its past roots while current research simultaneously promises to radically change its future. So, Dr. Lopes retraced his career with a calm voice and a friendly attitude. He likely introduced to Dr. João dos Santos, the founder of modern child mental health in Portugal, the last case of an autistic child he attended before died. He then suggested me to see an 8-minutes long film about João dos Santos' work with autistic children.

Some days after the meeting with Dr. Lopes, I finally found out the video, which since 2013 is available on Vimeo by the Centre for Multidisciplinary Studies - Ernesto de Sousa (CEMES). Film director and avant-garde photographer Ernesto de Sousa realized the film in 1967 at the request of Dr. João dos Santos. This mute documentary called *Crianças Autistas* (Autistic

Children) is filmed at the Dispensary of Infantile Mental Hygiene, a service belonging to the first Mental Health Centre for Children and Youth located inside the facility of the psychiatric hospital Julio de Matos in Lisbon. João dos Santos was at the time director of the Centre. The first scene that caught my attention concerned a woman, probably a psychologist or a nurse in civilian clothes, observing a child playing with a doll while a male assistant was trying to caress a 2- or 3-years old boy and then throw a ball at him. The area probably represents the maternage room Dr. Lopes was referring to. Another child was playing on the floor and rocking back and forth, then looking in the mirror he shows a serious face and then some funny grimaces. Then the woman sits next to him encouraging him to wave at the camera, raising his chin while the child nibbles his finger and rolls up a few strands of hair around his fingers. Another scene shows a male assistant smoking a cigarette surrounded by four nurses while discussing some of the children' designs scattered all around a table. Joao dos Santos eventually appears discussing a case with one nurse who enters his room with the first child who appeared in the video. Dr. dos Santos touches the child's head, then squats down and caresses his arms trying to invite him to get closer. Since the child is tangling his hair, Dr. dos Santos mimics his behaviour. The little boy eventually puts his own hand into the mouth of the doctor who gently shakes his little arms and finally lifts his face to direct his gaze towards him.

The short film reveals some of the therapeutic practices used with autistic children, as well as the medical team' coordination inside the facility. A Sunday late morning, while relaxing at the *Jardim das Amoreiras* surrounded by the magical shades of its mulberries, lindens, and ginkgoes, I bumped into João dos Santos' sculptured bust of stone and bronze. The garden is actually very near the Child Mental Health Centre where he worked and the Portuguese Gym Club, where he used to work out early in the morning. As sometimes our imagination makes people closer, I started visualizing Dr. dos Santos walking around the garden and calmly dialoguing with his friends, admiring the beautiful blue on white tiles panels or crossing the *Mãe d'Água*, the deposit that collects water from the *Águas Livres* aqueduct built by Hungarian architect Carlos Mardel.

Looking for a track toward the past

What have been the legacy of João dos Santos' work on the first generation of Portuguese child psychiatrists? In order to explore this topic and to draw a specific "local" history of autism, I examined the birth of Portuguese child psychiatry and the broader social and cultural conditions in which autism emerged as a distinctive object. In what follows, I will then anthropologically

investigate the socio-cultural configuration and the political environment lying at the background of autism's history as a psychiatric disorder and highlight the elements that contributed to the emergence of an interest in child population's mental care in Portugal during the early-20th century. This analysis will show how Portuguese child psychiatrists reacted to international biomedical entourage and to child psychopathology theories that were circulating at that time. Despite the dark time of Salazar dictatorship, Portuguese intelligentsia was indeed quite connected with broader international context. The relevance of the psychoanalytic roots of child psychiatry in Portugal will point out the reasons for the persistence of some of its concepts within autism diagnostic and therapeutic practices. This analysis will also show autism's vitality as a subject of investigation and as an "interacted" locus where parents and professionals (still) negotiate their views and experiences. As autism history is continuously produced at present time, ASDs represents a still working-in-progress label.

"The Secret of the Man is his own childhood"

"Every Man Keeps a Secret - the Secret of the Man is his own childhood" is the sentence that João dos Santos' disciples and colleagues chose to engrave in his bust, emphasizing the importance he gave to childhood: the "golden age" of mental health prevention. He represented a quite recognizable social figure of his time as, besides attending congresses and scientific meetings, he granted many press, radio and television interviews. Described as a fine connoisseur of the human mind, his disciples admired his inexhaustible source of knowledge and remembered him as a great storyteller (Costa 1991). A journalist, who covered one of his lecture of infantile psychiatry, mentioned his distinctive "didactic language", highlighting his abilities as a speaker. The article, published in 1965, reports part of his discourse:

"Child mental hygiene is one of the most promising branches of social medicine insofar as by giving support to parents through the respective services lets them understand that certain behaviours attributed to vices or bad education can be psychologically understood and psychotherapeutically solved (...) The psychiatrist is not an educator but thanks to his knowledge he may facilitate the creation of an educational environment more favourable to child development (...) Mothers must be protected so that the family has stability and provides a healthy development for the child. Education does not begin in the age of reason but in the cradle, when the child still receives from the mother only love and food" (Diário de Noticias de Madeira 1965)

This short excerpt shows some of the main topics of dos Santos' thinking, such as the pedagogical aims of child mental health professionals' interventions, as well as the role of the mother and of the family environment for the child well-being. His thinking has strongly influenced child psychiatry as a discipline and thus the way in which psychiatric conditions such as autism were thought.

During the Estado Novo, the authoritarian regime installed in Portugal in 1933 by Salazar (1933-1974), child psychiatry did not exist yet as an autonomous speciality (de Mendonça 2003:91). The Portuguese Medical Association eventually recognized it in 1959 with the designation of "child neuropsychiatry" (Fontes 1959). At the time, psychiatry was also mainly "practised" within the asylum, hence mental health care model was purposely targeted to this kind institution. Despite these unfortunate conditions, dos Santos succeeded bringing a new light to child's mental health sector. During his work between the 1940s and the 1970s, he promoted the development of child psychiatry as a speciality and his name is also associated with the birth of modern child psychiatry in the country. In particular, in 1964 he suggested a preliminary action to decentralize mental health care by promoting a network of mental health services around the country. The first *Centro de Saúde Mental Infantil de Lisboa* (from now on CSMIL) opened one year later in 1965. A multidisciplinary professional team led the centre, which represented "a turning point in the conception of child psychiatry and child mental health practice in Portugal: the centre was a flag, a model, a place of change and innovation" (Vidigal et al. 1999:28).

The CSMIL actually acquired the two children's pavilions located inside the psychiatric hospital Julio de Matos. Indeed, in 1944, the hospital director Antonio Flores have charged João dos Santos of organizing the two pavilions of the Infantile Section, which he eventually supervised until 1982. At the time, the buildings were quite exclusively assigned to the most "disturbed and psychotic children" (in most cases male) for whom there were no possibilities of therapeutic treatment (Nunes 1946). It seemed that the Infant Section was deemed to become a deposit of "deteriorated", "damaged", abandoned children and adolescents hospitalized for years (Vidigal 1995). Also, the lack of professional personnel prevented the access of treatable cases and risked turning these facilities into an infantile asylum. In this regard, in a 1945 Report dos Santos wrote:

“No special interest binds me to this Section other than the anguish of knowing that in Portugal thousands of children get lost in dementia for lack of properly trained psychiatrists and psychotherapists, of technical qualities and of the clinic itself (...) We do not know how much was spent with the Swiss nurses specialized in ergotherapy [Portuguese government paid a medical team from German and French Switzerland to guide the Portuguese team], the Infant Section is transformed into a deposit of idiots. There were even employees, patients’ guards, whose only requested “quality” was having the primary school diploma” (in Vidigal et al. 1999:93).

Despite the adversity, the Infantile Section represented a wind of change within Portuguese history of child psychiatry. João dos Santos claimed the necessity of turning the hospital environment more suitable and pleasant for young patients, as well as of training doctors, paediatricians and nurses in child psychology and psychiatry. Similarly, he urged authorities to briefly convert the two children pavilions into infantile psychiatric clinics (idem:64-68). Hence, the creation of the Centres for Child Mental Health was not an easy task to achieve. As I described, the roots of this project date back to the early ‘40s. The creation of the speciality of child psychiatry and of mental health services specially targeted for children represented two relevant occurrences for a better understanding of the relationships between mental health conditions and children. As far as concerned with my research, there was another emerging event that actually led to the emergence of a specific interest in autism: a more sensitive attention to infant population by the State and an increased surveillance over child’s development occurred during the early-20th century throughout Europe.

The first institution for the study of early childhood development

In Portugal, the landmarks that marked this new attention to childhood and its psychopathological states date even back to the 19th century (Nunes 1946:95–96), such as the creation in 1890 of the Deaf Institute of Benfica targeted for deaf and mentally disabled students, followed ten years later by the Institute *Branco Rodrigues* for blind people¹³. Despite the existence of these educational organizations, the history of child care and education in Portugal had to wait for the publication in 1913 of the work of António Aurélio da Costa Ferreira, clinician and pedagogue, to enter a new phase (Ferreira 1920). During the 1910s Costa

¹³ Despite not targeted for health or pedagogical purposes, it is also worth recalling the establishment in Lisbon of first House of Detention and Correction (also known as *Correcção das Mónicas*, 1871) for “disobedient” and “incorrigible” youngsters from age 18 to 21 (Miranda Santos 1970), and of the António Feliciano de Castilho Asylum-School in 1888.

Ferreira was the director of the *Casa Pia*, the largest educational institution - founded in 1780 by Queen Maria I - aimed at helping young people at risk of social exclusion or without parental support. Co-founder of the Portuguese Society of Anthropology and Ethnology, thanks to which he conducted anthropological studies in Mozambique, he eventually committed suicide in Maputo (formerly Lourenço Marques) in 1922 because of a nervous depression. As a pedagogue, Costa Ferreira promoted the investigation of specific childhood disabilities and introduced special education for both physically disabled and “abnormal” children (a designation that at the time included a heterogeneous group of children showing deviations from supposed normal developmental milestones). With this goal in mind, he founded two institutions for abnormal children, namely the *Colónia Agrícola de S. Bernardino* in 1912 and the Medico-Pedagogical Institute of Casa Pia de Lisboa in 1915 (Verissimo 2007). From 1918 to 1920 this latter served as a Centre for the Observation of wounded soldiers of I World War, then it resumed its purpose to include disabled children - the “nervous”, “stutterers”, and “mentally retarded” children (Fontes 1962) - in the educational system (Ribeiro 2009:198).

At the end of the 1920s, thus, the State partially assumed its responsibility for children educational care. Indeed, through a decree dated 1929 (No. 16.662), the Ministry of Public Education took the supervision of the Medico-Pedagogical Institute as a Special Education Centre for “mentally handicapped” children hosted at the Casa Pia. For the first time, children with mental “disturbances” or language difficulties could also benefit from external consultations. According to Fernandes (1979), Costa Ferreira supported an “anti-Jesuit campaign in the education sector”. In particular, Ferreira’s 1910 conference entitled *A Educação Moral e Religiosa nos Colégios dos Jesuítas* (The Moral and Religious Education in Jesuit Colleges) “constituted a violent accusation against the pedagogical approach of the Society of Jesus” (idem:37). He sustained and promoted, indeed, the work of those humanist pedagogues (such as Pestalozzi, Claraparede or Montessori) for whom school should not merely aim at correction but rather actively contribute to children’ moral and social growth. Renamed in 1929 as *Instituto António Aurélio da Costa Ferreira* (IAACF) in honour of its founder, the Institute started working as a training school for health technicians, providing for the first-time professional expertise and qualifications for doctors and educators willing to work with disabled children (Mesquita 2001:33–34). Overall, the IAACF played a pioneering role in implementing education care for children with disabilities.

In 1935 Vitor Fontes, a pupil of Costa Ferreira and professor of anatomy at the Faculty of

Medicine of Lisbon inherited the leadership of the IAACF implementing the work of his mentor. In response to his will to foster disabled children's social inclusion, during the 1940s Fontes authored a pioneering initiative to reform psychiatric assistance for children (Vidigal et al. 1999:53). Some legislative changes were indeed necessary to ensure access to appropriate care (Fontes 1962). For instance, in 1942 and in 1946 appeared respectively a Special Education program at the IAACF (Decree No. 32.607) and "special classes for abnormal children" at public schools (Decree No. 35.801). Moreover, the IAACF, which from 1942 also run a Dispensary of Child Mental Hygiene, coordinated infantile sections of psychiatric dispensaries (Ataíde 1947:302) thanks to the 1945 Law of Psychiatric Assistance (Law No. 2006), which reformed psychiatric care services (Coordenação Nacional para a Saúde Mental 2006). During Fontes' leadership, the Institute served three main functions. Firstly, thanks to the opening of external consultations and the establishment of social work service in schools, it was in charge of the observation and classification of abnormal children in the country. Secondly, it provided the medical team with specialized training courses, including courses on Child Abnormalities, Psychology, School Hygiene and Child Psychiatry, as well as a series of conferences on child neuro-psychiatry (1944-1952) later published as monographs (*Monografias do Boletim do IAACF*). Finally, from 1921 until 1941 the IAACF published the *Boletim do Instituto medico-pedagógico Casa Pia de Lisboa*, renamed in 1942 as *A Criança Portuguesa* and published until 1963, a bulletin aiding at research dissemination on childhood disabilities, medico-pedagogy and child psychiatry (de Mendonça 2003:94). These periodicals were divided into two structural parts: a first part included the publication of original papers based on medical observations and analysis of the young patients of the Institute while a second part contained bibliographic reviews of new international works and papers of foreign authors (such as Pestalozzi, Claraparede, Montessori, Piaget, Heuyer, Lutz), showing the concerted international fervour and relations of those years (Ataíde 1947:294–95).

The medical-pedagogy: childhood as a focus of governance in the early-20th century

So far, the analysis of these early twentieth century events shows that children's physical and psychological development was monitored and its supposed inherently problematic or abnormal forms identified. As I previously described, children suffering from physical or sensory impairments were the first to receive both education and care, as well as accommodation in nursing homes. Gradually, these services were also provided to those children who displayed mental or behavioural disorders. In this regard, the IAACF played a relevant role in this sense insofar as its medical staff was especially interested in studying

children with school maladaptation problems. Both psychiatrists and psychologists were indeed particularly committed to an ethic of pedagogical vocation, so much as that they conceived child mental health care as a prophylaxis's apparatus, namely as a preventive measure aimed at building a healthy adult population. Children with sensory or physical impairments, as well as with cognitive or behavioural problems represented disturbing elements of society and a social burden for the State. They needed "to be properly oriented, corrected or compensated, in order to have their function and place in society" (Fontes 1963:650).

In an article entitled *A psicossomática e a neuro-psiquiatria infantil* (The psychosomatic and the infantile neuro-psychiatry), Fontes (1948) argued how a lack of adaptation in children to the social environment represented a core symptom of most part of psychiatric patients and thus a treat to future social stability (idem:54). He further stated how "behavioural alterations, psychopathy, minor acts of antisocial content, maladjustment, which are clear signs of emotional attitudes and which easily lead to delinquency, poor school performance, maladaptation to family, school or job life" did not heighten Government concern as much as other social plagues such as alcoholism, syphilis, or tuberculosis (idem:59-60). Similarly, during a 1949 lecture in Madrid at the invitation of the Spanish Society of Paediatrics, Fontes addressed the "social impact of the psychopath" as "the top social problem within mental hygiene of the populations and as the most profoundly altered person in both affective and instinctive sphere" (Fontes 1952:88–89). This official medical reports and literature contributed fabricating new forms of surveillance and interventions on "deviant" children.

The medico-pedagogical vocation of primordial child psychiatry promoted thus an *orthopaedia psychica*, aimed at providing social and affective environments as a way of caring for the future of the nation (Vidigal et al. 1999:38–39). According to Armstrong (1995)

"the contemporary work of Freud that located adult psychopathology in early childhood experience can be seen as part of this approach. The nervous child, the delicate child, the enuretic child, the neuropathic child, the maladjusted child, the difficult child, the neurotic child, the over-sensitive child, the unstable child and the solitary child, all emerged as a new way of seeing a potentially hazardous normal childhood" (idem:396).

As childhood represented the fragile, vulnerable and ambiguous aspect of the adult's mental health, its abnormalities should have been attentively monitored and corrected in order to

“modelling of the ‘soul’ and of the behaviour of the child till adulthood” (Barahona Fernandes 1944:52). The observation of the soul-corrupted child (*criança transviada*) could reveal in advance the psychological path of adults (Fontes 1944). Having started his medical studies in the 40s, João dos Santos was strongly influenced by this conceptual approach: “the practice of child psychiatry” he wrote “is a way of preventing adult mental health, just as prenatal and early childhood prevention can avoid serious mental disorders of childhood, such as infantile autism, severe phobias, etc.” (dos Santos 2013:226).

The medical literature I mentioned so far considers childhood as the age the most inclined to “corrective” changes. By acknowledging and operating on her malleable nature, psycho-orthopaedic theories ended up by conceiving children as a testing ground. For instance, they emphasized the role of emotions in shaping children’s development. Since the psychic world owns “an exclusively affective and emotional aspect”, the child is highly affected by her social environment, which contributes “widening [her] emotional and psychic life thanks to the first contacts with others and especially with the mother” (Fontes 1948:56). This new specific attention to child’s affective environment contributes also to the emergence of a new conception of the family (Rose 1985:176). Parents have the responsibility of assuring their child protection, care and a healthy emotional environment. At this regard, since 1957 the IAACF organized periodic meetings with parents, called *Escola de Pais*, that aimed at sensitizing parents about education and care as a preventive measure for their children’ mental health (Fontes 1963:702).

Child psychiatry and special education pioneers, as well as the early formulations of medico-pedagogy for the treatment and education of feeble-minded children, were strongly influenced by hygiene movement and the evolution of education politics that made compulsory school widespread in Europe. A new class of childhood professionals inscribed children labelled as “retarded”, “maladjusted” and “emotionally disturbed” into categories following pedagogical criteria - whence educable / non-educable children - or according to social adaptation criteria - whence recoverable / non-recoverable children. These efforts to understand childhood pathology eventually led, as seen above, to the creation of community clinics and special schools for children. In her examination of the historical and social events that enabled autism to be identified as a distinct disorder in the early twentieth century, anthropologist Nadesan mentioned the increased forms of social surveillance on childhood - such as child guidance, compulsory education and mental hygiene movement - that turned childhood a “legitimate sphere of psychiatric inquiry” (Nadesan 2005:6). Also, Evans noted how in the same period

Britain endorsed a vast “expansion of charitable and governmental services to cater for the psychological problems of children” (Evans 2013:3). The emergence of this new medical gaze upon childhood has been also brilliantly analysed by Nikolas Rose in his 1990 book “Governing the soul” (Rose 1990). Child’s experts - such as psychologists, paediatricians, child psychiatrists, special education teachers - acquired competencies and knowledge to face a new class of children in special schools and child guidance clinics. As I previously analysed, Portugal followed the trend of a movement occurred in Europe with regards to education policy of the disabled children and medico-pedagogy. The IAACF represented, indeed, the place where this new knowledge was shared and where a new medical profession of early childhood specialists was trained (Vidigal et al. 1999:45–46).

João dos Santos and the first psychiatric care services

In 1940 João dos Santos enrolled in general psychiatry at the University Hospital - at that time part of the asylum Miguel Bombarda - under the guide of Barahona Fernandes while simultaneously started his child psychiatric training at the IAACF under the guidance of Victor Fontes (Branco 2000). Two years later, he presented his resignation as a psychiatric assistant at the IAACF to work at the Júlio de Matos Hospital at the invitation of his director António Flores. The relationship between these two institutions was at the core of the development of child mental health services: children with disabilities were, indeed, reported to the IAACF and the most serious cases sent to the Infantile Section of Julio de Matos (dos Santos 1948). In doing so, the IAACF provided the first statistical surveys on child disability. According to Ataíde (1947) among the 1609 children observed at IAACF from October 1941 to the end of 1946, only 243 were considered as “abnormal unrecoverable” and institutionalized along with adult patients in agricultural colonies, an alternative form of care provision¹⁴. The remaining 1,366 experienced a better fate. Those labelled as “educable” children were sent to special classes within public schools or to re-educational schools - such as the *Albergaria de Lisboa* (only for male children) and the *Instituto Condessa de Rivas*, created in 1926 and initially dedicated to the protection and education of poor female children “living in moral danger” (Nunes 1946:113) - while those considered as “medically treatable” and thus recognized as

¹⁴ Despite the label of “abnormal unrecoverable” present in this document, the idea of work as a treatment for mental illness was based on the belief that it was possible to tackle madness, as if despite its alien nature an individual could maintain at some level a rational being, which therefore made the cure possible. Generally, labour colonies were forms of experimental custodial care dating from the early 19th century. The first agriculture colonies were, indeed, introduced as psychiatric settings but also as penal colonies for orphans and juvenile delinquents.

“psychiatric cases” were sent to the Infant Section of the Julio de Matos hospital (Ataíde 1947:295–96).

In a report (1948) about his experience as director of the two pavilions, João dos Santos considered the opening of child psychiatric services inside the asylum as a temporary measure in order to improve clinical work and avoid the compulsory internment of children. He thus promoted the admission of treatable cases as they represented a fruitful material of research and observation about child psychopathology (idem: 25-29). For this purpose, the Infantile Section was equipped with a psychology laboratory and provided occupational therapy (gardening, care of pets, house-work, weaving) as a means of rehabilitation for children’ transition to professional training (idem:32–35). As I already outlined, dos Santos denounced the difficult conditions in which health professionals were working at the time. Psychiatrists, educators and nurses complained about mental health planning and accused the State to disregard their request for improvement of children’s hospital conditions (Branco 2014; dos Santos 1999). From the mid-20th century, the Portuguese medical professional was burdened by post-war period poverty, famine and orphanhood, which severely affected infantile population (Fontes 1948:63). During this period, the large decrease in infant mortality helped to inform health policy and child psychiatry on childhood health conditions, leading also to a theoretical critique and thus reformulation of classical psychopathological conceptions that did not fit with childhood issues (Vidigal et al. 1999:31). Despite some progress, in the mid-20th-century child psychiatry is still considered a bridge-discipline between general psychiatry and paediatrics and thus conceived as a minor expertise. Its subordinate position could explain, for instance, why João dos Santos was informed of the possibility to be paid less than a colleague with the same position when he accepted the position of director of the Infantile Section at the Julio de Matos hospital (idem:32–33). Outside the hospital context, dos Santos sought to improve early intervention for treating children with conduct problems and for this purpose, he also worked as a volunteer in schools with “difficult children” within some neighbourhoods of Lisbon (Branco 2000; de Mendonça 2003).

Because of his active engagement with child mental health and educational care politics, but also of his support for a democratic reform of the country, dos Santos endangered his own career. In 1945, he took part in a meeting - known as *Os 300 de Benfornoso* - that launched the MUD (Movement for Democratic Unity), a group that opposed the authoritarian regime. The growing influence of the MUD and its huge popular adhesion, combined with a strong anti-

communist action of the government, led Salazar to ban it in 1948. For this reason, a 1945 official ordinance dismissed dos Santos from his duties at the Julio de Matos Hospital, as well as prevented him from practising his profession in any other hospital in the country (Vidigal 2014). In a voluntary exile in Paris, between 1946 and 1950 he then completed a child psychology training at CNRS under the direction of Henri Wallon and became interested in psychoanalysis. An interest that will soon become a keystone of his future path. At this regard, Barahona Fernandes - a distinguished psychiatrist and teacher of dos Santos - acknowledged him to have first introduced “in a more systematic and rigorous way” a psychoanalytic approach in Portuguese child psychiatry (Barahona Fernandes 1984:20–21).

The psychoanalytic approach of João dos Santos during mid-20th century

France represented a fertile environment for dos Santos who was interested in the study of child development and psychology. For instance, he succeeded to collaborate with Henry Wallon’s Laboratory of Paediatric Psychobiology, as well as to work with Heuyer, who first introduced child psychiatry in France in 1949 as well as the practice of psychoanalysis in a hospital environment. He also worked at the Centre Alfred Binet - directed by psychoanalyst Serge Lebovici - where René Diatkine was introducing new psychodynamic frameworks at the time. In 1947, he joined the SPP (Psychoanalytic Society of Paris) and embraced psychoanalysis as a professional training and orientation. He used to describe it as “the acceptance of the child that exists in each man and the art of allowing each one to reconcile with his own childhood” (dos Santos 1969:143), a description echoing the sentence sculptured in his bust. When he eventually moved back to Portugal in 1950 - thanks to Barahona Fernandes who invited him to work at his private clinic - dos Santos had, therefore, already experienced a different approach to child mental pathology. His enthusiasm, however, crashed with the theoretical backwardness of Portuguese medical environment and the lack of professionals with psychotherapy training.

Actually, Freud work - such as his study of the child’s affective life - was already known in Portugal during the 20th century (Fontes 1956) but according to Martinho (2003) was censored or received a cold reception because of the cultural backwardness and extreme Catholic background of the country. For instance, the first Portuguese edition in 1932 of the 1905 Freud’s Three Essays on the Theory of Sexuality provoked “public outrage” (Martinho 2003:1). Despite this, Morbeck and Pereirinha (2016) mentioned early 20th-century psychiatrists Sobral Cid and Edgar Moniz as belonging to so-called Portuguese “prehistory of the psychoanalysis” (Luzes 2002). While the first one suggested the use of the psychoanalytic method for the observation

and treatment of both psychotic patients and law offenders¹⁵, the future Nobel Prize for Medicine was the first to actually introduce Freud during his 1915 Neurology Course's inaugural lecture about the foundations of psychoanalysis and even applied the psychoanalytic method to two of his clinical cases (Morbeck and Pereirinha 2006:15).

The contribute of Joao dos Santos relied on his innovative use of psychoanalysis. Besides to employ psychanalysis as a method of observation, he created a before a pioneering “children observation laboratory” and implemented the use of psychotherapeutic techniques unprecedented for that time in Portugal (de Mendonça 2003:95–96). Moreover, he provided psychoanalytic training to the first generation of specialized nurses and child psychiatrists at the Female Infantile Clinic¹⁶. Here organized from 1958 seminars for health professionals and educational technicians where he introduced the work of influential child psychiatrists and psychoanalysts of the time, such as Anna Freud, Melanie Klein, Spitz, Bowlby, Aubry and eventually of Leo Kanner (idem:98). The diagnostic process also prescribed to interview parents and observe their behaviour with children, a method that suggested the idea of a relationship between parenting and children' relational issues or psychopathology. Similarly, psychotherapy was essentially family-oriented and provided by a multidisciplinary medical team supervised by João dos Santos himself.

So far, I emphasized the role of dos Santos in child psychiatric care's improvement as well as in psychoanalysis' spread among medical practitioners. Besides these innovative impacts, child's mental health in Portugal was also faced social challenges and serious material difficulties. Until the mid-60s, indeed, dos Santos kept addressing the authorities in order to denounce the dehumanized living conditions of children inside the hospital:

“Children with severe mental and motor deficits (...) get worse day by day. They can not recover given the lack of “affective” assistance, of personnel and of professional competencies (...). Food is absurdly improper (...) Last winter I did not get water heating nor general heating for the pavilion. Children have to be cleaned in cold water because (...) there is no time to heat water in pans. Under these conditions, children cannot be cleaned whenever they get dirty. [Due to

¹⁵. In particular, it is worth mentioning two volumes authored by Sobral Cid entitled respectively *A Vida psíquica dos esquizofrênicos* (1924) and *Psicopatologia criminal: Casuística e Doutrina* (1934).

¹⁶ The *Clinica Infantil das Meninas* was actually the former feminine pavilion of Infantile Section at Julio de Matos Hospital. Here children of both sexes received clinical treatment, while the masculine pavilion was mainly disposed to hospitalization.

lack of personnel] patients themselves help in various tasks (...) and this help is becoming dangerous” (dos Santos 1999:98–99)

He even reported the death of a child likely due to a collapse after other children involuntarily gave her a bath in extremely cold water as well as how older children were often feeding the younger ones. Public institutions targeted for child’s care and education needed to be reformed and improved in order to be more accessible and democratic. Ultimately, this represented a real political challenge.

The heritage of João dos Santos for modern infantile psychiatric care

Despite its awful conditions, the chronic lack of human resources and even some episodes of escape from the hospital, the children’s ward was considered a happy “island” inside the Julio de Matos psychiatric hospital (Vidigal et al. 1999:120–25). During the ‘60s Margarida Mendo - the first “official” child psychiatrist graduate in Portugal - took dos Santos’ place as director of the Infantile Section. The creation of a Day Hospital service inside the hospital, which was led by a team of different technicians (psychiatrists, special need teachers, and psychologists), eventually provided (1) an observation and monitoring service (preliminary to an eventual hospitalization) and as (2) a facility where children with severe but still treatable psychopathologies were treated.

During this decade, the majority of the hospitalized children (around 60 people, most of them older than 15 years of age) was considered chronic mentally ill and affected by oligophrenia, psychoses, severe forms of epilepsy, schizophrenia and autism. Besides more traditional treatments (psychomotricity and occupational therapies), new specific psychotherapeutic interventions started to be practised for the first time. Among these, the maternage (namely mothering therapy) aimed at recreating the complex attitudes and actions involved in the mother-child relationship. This technique was mainly used with children who supposedly presented severe relational problems, a tendency to isolation, and difficulties in emotional contact. Children showing early psychoses and autism - this was indeed still thought as a psychotic symptom - were especially supposed to benefit from this intervention (idem:124). The attachment relationship with caregivers is the initial context in which a child’s emotional life unfolds and emotional skills are developed, setting the stage for the child’s future social relationships. Consequently, most part of the therapeutic interventions aimed at helping parents to promote their child’ emotional growth and to heal them from (supposed) emotional scars.

It is within this same period that dos Santos and his disciples stood for a de-localization of hospital-based care and for the establishment of outpatient service centres in order to guarantee and improve the provision of child mental health services and treatments to a broader community. As I mentioned at the beginning of this chapter, the opening of the first CSMIL takes place in 1965. Besides the use of specific biomedical techniques (laboratory tests, X-ray, electrocardiography, endoscopy, blood analyses), the interdisciplinary team followed a psychoanalytic-based approach to diagnosis and treatment. Also, services and assistance were mainly family-oriented. Since mental health begins early in life, with early experiences shaping the psychic and emotional architecture of the child, the family environment was supposed to be at the heart of the child's wellbeing. This focus on the family provided some support and protection to children, whose families felt and lived with guilt and shame because of the social stigma associated with mental disorders and intellectual disabilities. Fontes (1969) for instance argued that child psychiatry may contribute to assure disabled children "the right to occupy a place" in society, considering that because of social stigma families used to send children with disabilities living with servants or (in the case of more affluent families) in foreign mental facilities (idem:5).

The understanding of the child and of her conflicts could be effective, therefore, only after the comprehension of her family dynamics and of their relational and affective patterns. Along with emotional growth, child psychiatrists made child's education development another main purpose of their work with families. Educational environment was, indeed, a prerequisite for therapeutic interventions, fostering the close relationship between the mental health services and the educational system that characterized the medico-pedagogical approach of child psychiatry. The discrimination children suffered at school because of neglect or of their own learning difficulties deeply affected dos Santos, who has had first-hand experience of being marginalized and bullied because of his dyslexia. His own experience has an impact on his future concern for a reform of the educational system, characterized by schools' inadequate conditions and severe teaching methods. His holistic approach to children emotional, psychological and social well-being explains also his fascination with sports, camping, and nature, activities that his father promoted during his childhood. Indeed, he began his professional life as a gym teacher working on the physical rehabilitation of children with developmental problems (de Mendonça 2003:92–93).

Dos Santos' commitment to foster educational attainment and improve the quality and availability of educational child care represented thus another fundamental axis of his legacy. In order to implement his ideas and to provide health and educational services to disabled children, as well as legislative support to their families, he eventually contributes to creating a network of different institutions. Among them, the *Voz do Operário* (1932) and the Modern College (1936) - the first two psycho-pedagogical centres founded in Portugal - and the *Claparède* College (1954), as well as institutions specifically targeted to physically disabled children (such as the Physically Disabled League, the Helen Keller Centre and the Deaf Portuguese Association). In 1975, he also founded the *Casa da Praia* (1975), an institution providing a space of transition between the familiar environment and the formal school environment. Initially conceived as a specialized service of the CSMIL, from 1992 the Casa da Praia is a private institution with social solidarity aims. Since here education and health were conceived and practised as real complementary sectors of interventions, "care by educating" soon became the slogan of its approach (Magalhães 2013). This institution is also led by a multidisciplinary team committed to a "therapeutic pedagogy" able to help parents, educators and special needs teachers to consider children's specific abilities, their own rhythm of learning and their motivations (Barros 1999). On educational care, he also produced a copious scientific literature later published in two volumes entitled "Essays on Education" (dos Santos 1991a, 1991b). During the early '80s, he participated - in joint partnership with several doctors, judges, teachers, psychologists, social workers, and educators - to the creation of the *IAC - Instituto de Apoio à Criança* (Child Support Institute), which aimed at the promotion and defence of children's human rights. Many of these institutions still exist today thanks to the driving role of his pupils.

In this last section of the chapter, I retraced the roots of Portuguese child psychiatry by focusing on João dos Santos' theoretical legacy for modern child psychiatry. I outlined, in particular, the impact of his psychoanalytic-oriented approach on child psychopathology's conception and treatment, as well as the pioneering establishment of the first network of outpatient mental health services for children. Furthermore, child psychiatrist's attentive ability to observe not only child's behaviours as well as her emotional and corporeal relationships with others but also her family environment represent a diagnostic method still claimed by some contemporary child psychiatrists. This medical-pedagogical approach towards children and their own parents shows the crucial role attributed to family environment and affectivity in shaping child's development and wellbeing. On this topic, I have underlined how therapeutic interventions

especially focused on early mother-child relationships: the insurgence of a child's emotional and behavioural disorders was, indeed, associated with disturbances in the emotional attachment with primary caregivers (de Mendonça 2003:100).

Chapter II

Autism's foundations in Portugal and the first parent-led association

In the preceding chapter, I briefly mentioned how the main proposal in the psychoanalytic approach to child psychopathology concerns the central role granted to mother-child interactions and family context. Earlier conceptions of autism, indeed, closely tangled with narratives on the parental role in childcare. During the 1940s Kanner firstly described autism as a “disturbance of affective contact” caused by parents showing little involvement with their children. From the 1950s through to the 1970s, the prevailing view was that autism was the product of mothers who were cold, distant and rejecting (Silverman 2012; Wolff 2004). Aetiology theories of autism have deeply evolved over the time and these earlier conceptions have long been discredited. So, autism is nowadays mainly understood as a spectrum of neurodevelopmental disorders, resulting from neurological impairments and likely genetic factors. Despite giving credit to this latest conception, Dr. Lopes classifies and thus understands autism as a relational disorder, showing how the idea of autism as a consequence of a social-relational disorder still gains some acceptance. In what follows, then, I will attempt to show when, how and under which conditions autism appeared in Portugal and explore more deeply the specific transformation of its understanding during the time. This exploration will contribute to a local historical account of autism by highlighting how a certain approach to autism still persists in current Portuguese child psychiatry. Existing social science and medical literature on the topic, including Master and PhD theses, monographs, and scientific articles, did not clarify the specific conditions of emergence of autism in the country, listing instead its official nosological changes. Finally, I will illustrate the birth and development of parents' autism associations and show how this event is directly linked to parents' willingness to favour a biological explanation of autism at the expense of any psychogenic theory.

The path of autism in Portugal

Making and describing the meaning of autism - whether as a diagnostic category, as a descriptive concept of child development, or as an intellectual disability - still represents a controversial issue. In order to detect the wider socio-cultural and political changes that affected autism transformation as a diagnostic category and to explore its emergence within Portuguese

context, I started a review of scientific biomedical literature of the 20th century (including textbooks, scientific journals' articles, health surveys, medical reports, and hospital discharges)¹⁷. In addressing this historical archive, I gave relevance to those names and institutions that revealed to be peculiar or specifically related to autism historical evolution. Child psychiatry as a science and discipline also reflects the sociocultural and political characteristics of its time. This is why, this historical exploration will highlight not only specific biomedical approach to child mental disorders but also social representations of childhood, motherhood, family, as well as social behaviour and normality.

From a psychotic symptom to an isolated psychiatric disorder

The question guiding this chapter is: what social and historical forces have favoured and conditioned the appearance of autism in Portugal? The development of an expertise in children's mental health and the following establishment of a targeted set of care treatments and infrastructure is, as I already exposed, the result of different social, epistemological and political factors. Among them, I mentioned the emergence of a public responsibility to children and adolescents in need of care (Chapter I). The history of child psychiatry is inextricably linked, indeed, to the recognition of children's role in society and of childhood as a distinct and crucial period of development. In his study on autism and the idea of sociality, Hollin (2014) argued that increased surveillance over the mental health of the child from the early 20th century and the consequent production of knowledge on childhood were a "prerequisite for the emergence of autism" (idem:100). This event, in other words, provided the conditions for autism to emerge as a category. As expressed by Armstrong (1995),

"[while] hospital Medicine was only concerned with the ill patient in whom a lesion might be identified [...] the cardinal feature of Surveillance Medicine is its targeting of everyone. [It] requires the dissolution of the distinct clinical categories of healthy and ill as it attempts to bring everyone within its network of visibility. Therefore, one of the earliest expressions of Surveillance Medicine - and a vital precondition for its continuing proliferation - was the problematisation of the normal" (idem:395)

The space and the target of the medical gaze gained, thus, a new dimension. In the 20th century, the child "became the first target of the full deployment of the concept [of surveillance]"

¹⁷ Medical literature archives were consulted for the most part in the repositories of the *Biblioteca Nacional de Lisboa*, whose Documentation Services provided me assistance during the research.

(idem:366) and the attention on her appropriate growth justified the close medical observation through the establishment of specific services (day nurseries and infant clinics) and the introduction of monitoring techniques, such as screening, health surveys, and public health campaigns (idem:403). This focus on child developmental represents a fundamental element in autism construction as a disorder insofar as “in contemporary cultural narratives it is the child who carries the weight of what we wish to say or think about the condition, and it is through a focus on children that autism is increasingly being understood” (Murray 2008:139).

In early and mid-20th century Portugal, the institution charged with the observation and treatment of child population was the IAACF. For this reason, among the archive material that I collected in order to trace autism’s appearance in the country, I paid particular importance to its two bulletins, the *Boletim do Instituto medico-pedagógico Casa Pia de Lisboa* (1921-42) and the *A Criança Portuguesa* (1942-1963). As I mentioned in the previous chapter, both periodicals intended to scientific articles on child mental health and care issues, as well as to disseminate reports based on direct observation and treatment of the young patients of the Institute. The general consideration arising from my first analysis is that psychologists and psychiatrists did not use the same terms nor adopt the same criteria to classify children supposed mental disorders and behavioural problems. This lack of uniformity did not actually surprise me. First, the range of different labels reveals the attempts to understand child’s psychopathology and to systematize its complexity into a different taxonomy. At this regard, 20th-century psychologists and psychiatrists considered adult’s mental illnesses as the product of child’s psychological evolution and thus looked at child’s psychological states as the locus where to observe pathology in its birth. As a result, infantile psychopathology was initially understood as an early manifestation of adult mental disorders. Several articles explicitly refer to this idea. Barahona Fernandes (1944), for example, distinguished several types of psychoses - such as the “insecure, sensitive, autistic, amoral, and insensitive” types - whose insurgence could be dated back to childhood, when social environment deeply affect the differentiation of the child’s psychic functions (idem:43-5). This reference perfectly encapsulates two important issues. First, the earlier generation of child psychiatrists employed the extended concept of “psychoses” to refer to children’s psychopathology of affectivity. Second, until the mid-20th-century the term autism stands for a type of psychosis or a symptom of childhood schizophrenia.

The term autism - from the Greek word *autós* (αὐτός, meaning “self”) was, indeed, coined by the Swiss psychiatrist Eugen Bleuler in 1910 to describe a core symptom of schizophrenia: an

“autistic withdrawal of (a) patient to his fantasies, against which any influence from outside becomes an intolerable disturbance” (Kuhn and Cahn 2004:364). Autism represented a secondary symptom of schizophrenia, a chronic condition of evolutionary nature affecting the cognitive capacity and the affective sphere (Pereira 1983). In his article “Autistic Disturbances of Affective Contact”, Kanner (1943) takes the term autism from Bleuler to designate an independent *syndrome* (in italic in the original text) affecting children who show an inability to relate. He further argued how

“this is not, as in schizophrenic children or adults, a departure from an initially present relationship; it is not a “withdrawal” from formerly existing participation. There is from the start an *extreme autistic aloneness*, that, whenever possible, disregards, ignores, shuts out anything that comes to the child from the outside” (idem:242).

Relating his observations of children’s families, Kanner reported the how these children have “highly intelligent” and “few really warm-hearted” parents. He thus suggested that parenting might contribute to the development of autism, balancing this suggestion with the observation that children’s aloneness was present very early on, making it difficult to “attribute the whole picture [of autism] exclusively to early parental relations” (idem:250). Despite the suggestion that autism may result from an inborn defect of presumably constitutional origin, over the next 30 years “the possible role of genetic factors tended to be dismissed” (Rutter 2000:3).

Kanner, a Jewish Austrian graduated at the University of Berlin and later established in the USA, described autism according with a psychoanalytic approach. By forcing Jewish psychoanalysts in occupied Europe to emigrate, the Nazi persecutions shifted the core of the movement to the USA¹⁸. Here, starting from the II post-war era and thanks to European refugees, psychoanalysis became dominant and regained popularity also in Europe (Plant 2005:182), contributing to its international expansion. At the time of the publication of his renowned article, Kanner has already founded the first child psychiatry department (1930) under the direction of Adolf Meyer at the Johns Hopkins Hospital in the USA, and his textbook

¹⁸ The other 2 main factors to be mentioned as contributing to psychoanalysis expansion are: the Freud’s death in the outset of the war, which made psychoanalysts responsible for what would or would not be considered as strict psychoanalytic, leading to a more democratic structure within the movement; and the Allied victory in 1945, that by spreading American culture in Europe, renovated the interest in psychoanalysis (International Dictionary of Psychoanalysis n.d.).

“Child Psychiatry” (1935) has already introduced the speciality to the Anglophone academic community.

In Europe, Lutz is the first to refer the notion of childhood schizophrenia¹⁹ as a distinct entity at the 1st International Congress on Child Psychiatry, held in Paris in 1937. This international event is commonly referred to as the official “debut” of child psychiatry as a discipline. Portugal will recognize child psychiatry as a speciality only in 1959, testifying the difficulty of child mental health professionals of the time to gain legitimacy within the broader scientific environment. Fontes and Barahona Fernandes - the only two Portuguese representatives present at the Congress - did not address conference’s topic on child behavioural disorders because, as Fontes himself argued, “the recent formation of child psychiatric services and the lack of institutions aimed to follow disturbed children did not allow us to have a reliable opinion on the adaptive evolution of those disturbed children” (Fontes 1950:455). Instead, Barahona Fernandes delivered an off-topic speech “Impact of war on youth in a country that did not participate in war” based on a study carried out with Ataíde and dos Santos. During the mid-20th century, Portuguese psychiatrists became more acquainted with psychoanalytic thinking. In several articles, Fontes underlined the role of family and social environment in the evolution of childhood psychoses, as well as the crucial role of child’s early emotional experiences in her future psychic development (Fontes 1948, 1952, 1956). During the 1950s through the 1960s, etiological hypotheses hold that “autism was due to an emotional disturbance deeply rooted in abnormal parent-child psychodynamics, such as an infant’s response to an emotionally cold and distant mother” (Mintz 2017:45). Child’s autism was, in other words, a defence mechanism in response to extremely stressful situations due to a poor emotional environment. As a result, autism-related treatments were mainly family-centred. Despite no cause-effect relation was yet demonstrated, as Kanner himself suggested in his clinical cases discussion, psychogenic explanation gained authority.

In a 1955 article on childhood schizophrenia published in *A Criança Portuguesa*, Corboz - who was working at the Child Psychiatry Service of the University of Zurich - argued that “the total absence of affective contact must be considered, according to Freud, of a psychotic nature”

¹⁹ There was at the time two main aetiological explanation of childhood schizophrenia. While some psychiatrists generally supported an organic view of infantile schizophrenia, caused by hereditary and other acquired factors (such as birth trauma or infectious diseases), others favoured a psychogenic hypothesis, arguing that the main cause was a deep alteration of the mother-child relationship in the first year of life.

and that schizophrenic children's "aggressive tendencies are fought by taking refuge in autism" (Corboz 1955:80). In his clinical observations, he also observed a lower prevalence of childhood schizophrenia (1-2%) in comparison with USA rates. This data led him to conclude that while in the USA several child syndromes - such as Kanner's early infantile autism and Asperger's "autistic psychopathy" (a form of autism that does not affect cognitive abilities) - still fell under the same category of childhood schizophrenia, European psychiatrists considered the two syndromes within the nosologic framework of childhood psychoses of the affective sphere (idem:78) and separated these latter from childhood schizophrenia as they did not develop dementia nor personality disintegration²⁰ (Lyons and Fitzgerald 2007). In a paper comparing Corboz's findings to the Portuguese context and presented during the Child Psychiatry Session at the 2nd International Congress of Psychiatry in Zurich (1957), Portuguese psychiatrists Fontes and Ataíde reported only 4 diagnoses of childhood schizophrenia among the 8300 clinical cases examined at the Dispensary of Mental Hygiene Infante of the IAACF. They also pointed out how up to the date of the conference - 1957 - there were no diagnostic cases of Kanner's early infantile autism so that in their clinical cases' description they still use the term autism to refer to a childhood schizophrenia's symptom (Fontes and Ataíde 1958:278).

In 1958 Portuguese child psychiatry gained national and international attention in the wake of the 4th International Congress of Child Psychiatry, held in Lisbon and presided over by Vítor Fontes. The analysis of the meeting's minutes also shows psychiatry's opposite viewpoints about the origin of child behaviour problems. During a conference's parallel session, for instance, French psychoanalyst and psychiatrist Lebovici complained about the polarization that existed between psychogenic and organic explanations of children's mental disorders (Aa. Vv. 1958:430). This controversy particularly affected autism's conception as a result of the existing "splitting" in the organic and psychic concepts of its aetiology. At this regard, Nic Waal - known as the leading figure of Norwegian psychoanalytically-oriented paediatric and adolescent psychiatry (Erwin 2002:383) - answered to Lebovici's complain by stating how in her own clinical experience children diagnosed with an organic brain disorder with autistic features usually show a better prognosis than autistic children per se. According to her, this is due because organic diagnosis relieves parents' "guilt feelings", leading them to "therapeutically cooperate much better than parents who do not find any concrete explanation of their children disease" (Aa. Vv. 1958:432). During the following conference's film section,

²⁰ Hallucinations and delusions, which are features of schizophrenia, are not features of autism spectrum disorder.

Waal herself presented a film entitled “Experimental treatment of autistic children” while René Spitz (from the USA) presented two films titled “Mother-Child Relationship” and “Genesis of the emotion” (a study on children’s smile response to their mothers), showing the fundamental opposition between organic and psychogenic viewpoints of autism at the time. As I already pointed out, psychoanalysis thinks Kanner’s early infantile autism as a childhood psychosis²¹, characterized by a perturbation of first object-relations²², namely with the mother: “the child perceives and recognizes the objects, but does not give them any differentiated emotional value. In particular, he does not differentiate the face of his mother, as well as of other animated beings, from inanimate objects” (Lebovici and Diatkine 1963:112).

Autism and schizophrenia share a long and tangled history. Until the mid-20th-century many clinicians used autism and childhood-onset schizophrenia interchangeably. In particular, the scientific literature of the time employed the term autism or autistic to indicate a psychotic symptom affecting child’s affective sphere. This understanding arose from the psychoanalytic theories of the period, which conceived child’s mental processes, her experience and behaviours as influenced by social and environmental contributions. As a result, autism was thought as a disturbance of the affective contact caused by poor rearing environments, and especially by a lack of maternal warmth (being the mothers usually the primary caregivers of infants). In line with this conceptual frame of reference, psychotherapeutic approaches share the assumption that child’s psychological disorders are rooted interpersonal conflicts and thus therapies (such as maternage, family-oriented therapies and occupational therapies) aimed at improving her emotional responsiveness. It is also attested, however, the use of other well-established psychiatric treatment procedures, as shown by a 1960 article where “autistic symptoms of childhood schizophrenia” were treated with insulin and electric shock therapies (Fontes et al. 1960).

²¹ Child psychiatry also employed the term of pre-psychosis to indicate the period from the onset of a manifest psychosis to a likely transition to adult psychosis (Lebovici and Diatkine 1963:109–10). However, psychotic symptoms in childhood do not necessarily develop adult schizophrenia, and conversely, adult schizophrenia does not always originate from early childhood psychosis.

²² The Object relations theory refers to the process of developing an emotional attachment in relation to others during childhood, being that the first “object” is usually an internalized image of one’s mother or primary caregiver. This theory emphasizes thus interpersonal relations, primarily in the family and especially between mother and child. In psychoanalysis, the term “object” actually means a significant person that is the object or target of another’s feelings or intentions. The term “relations” refers to interpersonal relations that affect a person. Object relations theorists, thus, are interested in inner images of the self and other and how they manifest themselves in interpersonal situations (Daniels 2007).

So far, the qualitative review of Portuguese child psychiatry scientific literature of the first half of 20th century showed a progressive interest in autism, as well as the huge contribution of first child psychiatrists' generation who, by acknowledging child population as in need of their attention, surveillance and care, started to diagnose and thus report “autistic symptoms” in related literature. From the mid-20th century, the notions of childhood psychosis and autism changed in accordance with the emergence of a new understanding of child psychopathology spreading all over Europe. In particular, from the 1960s and 1970s psychogenic theories of autism began to fade as soon as genetic and neurophysiological research²³ took forward the idea of autism as a neurological disorder (Mintz 2017:45)²⁴. Despite this, the overlapping between childhood schizophrenia and autism lasted until then. Indeed, we have to wait for the publication in 1980 of the DSM III to see for the first time “infantile autism” listed in a category (pervasive developmental disorders) officially separated from childhood schizophrenia. Both technological and theoretical advances have influenced the evolution of autism as a discrete condition. Along with its history, therefore, the different conceptions of autism gained different *niches of temporary legitimacy* in accordance with the particular historical and socio-political context and its-related epistemological paradigms.

Despite the attention that cognitive and neurological conceptions of autism started to gain among Portuguese child psychiatrists from the second-half of the 20th century, the influence of psychoanalytic approaches has endured. In the next paragraph, I will show, indeed, the persistence and impact of this influence till nowadays.

The persistence of the psychoanalytic account of autism (1960s-2010s)

In the late 1960s, Ataíde (1968b) - who at the time worked as a psychiatrist at the IAACF - mentioned the existence in Portugal of two approaches towards childhood psychopathology and its supposed causes. On one hand, the well-known psychoanalytic approach of Lebovici and Diatkine - represented in Portugal by João dos Santos and her disciple Celeste Malpique -

²³ It is worth mentioning, in this regard, genetic findings on high concordance rates of autism in identical twins and on incidence and prevalence of epilepsy in autism (Eshkevari 1979; Freitag et al. 2010; Gupta and State 2007; Muhle, Trentacoste, and Rapin 2004), as well as neurophysiological research on brain abnormalities in autism (Bishop 2008).

²⁴ These years will be also particularly crucial for the future of the discipline (Shorter 1997). For instance, the anti-asylum movement and more generally the demand for a more humane approach to psychiatry (Desai 2005:185) challenged the moral and legal legitimacy of confinement and coercion within institutional psychiatry (Szasz 2006:5). Psychoanalysis still represented the main training model for psychiatrists, influencing children's mental care conceptions and treatments (Fine 1990; Shapiro and Esman 1992). Many psychoanalysts worked as psychiatrists at universities' Departments of Psychiatry, as well as at hospitals, as illustrated by the Portuguese case of João dos Santos and its first generation of child psychiatrists.

asserted that childhood psychoses involve a psychogenic mechanism determined by early disturbances in the mother-child relationship. On the other hand, whilst recognizing the impact of the relational context in the emergence of a psychosis, other child psychiatrists such as Lutz, Corboz, Heuyer and Ataíde himself consider autism and childhood psychoses as endogenous conditions (idem:6-7).

As a result, plenty of mental health professionals still practised psychoanalytical-oriented child psychiatry. The tenacity of the psychodynamic account of autism lasted several decades and it is evidenced by the enduring overlap between autism, psychosis and childhood schizophrenia, the crucial role still ascribed to the mother-child relationship for the child's psychological and emotional development, as well as the lasting popularity of psychotherapy.

Several medical reports describing clinical cases of infantile psychosis refer to a broader "autistic symptomatology". Until the late 1970s, the term "psychosis of autistic type" or "psychosis with autistic-type behaviours" implied the idea that autism was a "disturbance of affective contact" due to a deficit in early mother-child attachment process. In particular, autism is still defined as a reaction of the parents' "coldness and intellectualism", which inhibit them to "externalize their affections" (idem:20), as well as a psychotic response to the profound disruption of the mother-child relationship (Ataíde 1969:30–31). The term "autistic behaviour" is also mentioned as a symptom of child's neurosis, early dementia and oligophrenia, or to refer to abandoned children's lack of affectivity (Ataíde 1971b:459). Similarly, a person with a oneiric level of consciousness - a state similar to that of light sleep - is described as absorbed in her thoughts and feelings, and living "in a world that, in a certain sense, can be called autistic" (Ataíde 1971a:101). Mentioned as a form of "alteration of personality", autism could also describe the condition of who "lives in a different world, from which observes others with irony and contempt" (idem:145). The overlapping with childhood schizophrenia persisted. Again, Ataíde described "autistic tendencies" or "attitudes" of a schizoid child who "is emotionally solitary, taciturn, reserved, cold, shows a tendency to introversion or to a psychic internalization of the Ego, and thus to autism" (idem:80). Similarly, the first Manual of Child and Adolescence Psychiatry published in Portugal in 1977 still merged autism into the "psychoses of childhood and adolescence" (Ataíde et al. 1977). In a 1978, paper Maria João Miguéns and Antonio Coimbra de Matos - who took dos Santos' place as director of the CSMIL - referred to a clinical case of "autistic psychosis" and argued that "autism and schizophrenia are one and the same disease, but each with its own evolutionary period" (Coimbra de Matos and Miguéns 1978:3).

The authors consider infantile autism as a childhood psychosis in which the “symptom of autism” is so intense and persistent that relationship and conduct are deeply disturbed. Furthermore, they think infantile autism differentiates from childhood schizophrenia for the age of onset. While childhood schizophrenia appeared in latency age (from about five years to puberty),²⁵ infantile autism was considered as a pre-oedipal psychosis, which differed from Kanner’s syndrome for its richer and more florid symptomatology similar to classic schizophrenia.

Even in late 90s, when autism is already accredited as a developmental disorder with likely genetic origins, Gonçalves (1992) - despite acknowledging DSM III new diagnostic category of pervasive developmental disorders - considered autism as a “symbiotic psychosis” originating from mothers’ difficulties to develop empathic responses to her child’s necessities and desires (idem:98). Similarly, Coimbra de Matos (1997) still understood autism within the framework of “early childhood psychoses” (idem:27).

As mentioned before, in Europe till the 1960s autistic disorder were believed to have relational and environmental origins. However, from the 1970s the psychogenic theory of autism started losing ground to biologically-oriented research (Folstein and Piven 1991; Rutter 2000). Actually, Bernard Rimland, a father of a so-called high-functioning autistic son and founder in 1967 of the Autism Research Institute (ARI) in the USA, was the foremost supporter of a biological origin of autism with his 1964 book “Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behaviour” (Rimland 1964). Yet, his efforts did not prevail over the authority and popularity of the theory of “refrigerator mothers”, a label for mothers blamed for being the cause of their children’s autism because of a lack of their maternal warmth. The origins of this idea dates back to Kanner himself, who after having speculated in his 1943 article a link between autism insurgence and poor warm-hearted parents, suggested in a 1949 paper that autistic children were exposed to “maternal lack of genuine warmth” (Kanner 1949:422), to “parental coldness, obsessiveness, and a mechanical type of attention to material needs only (...) [and] kept neatly in refrigerators which did not defrost. [Thus] Their withdrawal seems to be an act of turning away from such a situation to seek comfort in solitude” (idem:425). But it was with Bruno Bettelheim that the theory gained widespread acceptance both by the

²⁵ According to Freud, child’s psychosexual development follows five stages (the oral, the anal, the phallic, the latency, and the genital phases). Each stage corresponds to a different body area towards which the child discharges her sexual energy (libido).

public and the medical establishment. For the author, autism could be the consequence of mother's wish that her "child should not exist", even if this desire did not necessarily cause autism in all children, suggesting that autism might be pre-determined by an organic factor (Bettelheim 1972:125). Bettelheim's theory has been one of the reasons raised against psychoanalytic thinking insofar as it blamed mothers for their children's autism. These critics, however, ignored that he based his theory on the analogy between his own past experience in the Nazi concentration camps of Dachau and Buchenwald and the mental functioning of the autistic. He related indeed the world of emotionally deprived autistic children to the living conditions in concentration camps. In order to explain autistic children's experience of lack of affectivity, he employed the concept of "destructive extreme situation", originally created to refer to the dehumanization of the individual in the concentration camps and to devastating effect of emotional deprivation (for a critical review of Bettelheim's legacy see Silverman 2012 Chapter 2)

Eventually, genetic research undertaken in the 1970s and 1980s indicated both strong genetic influences in autism insurgence, challenging the framework in vogue at that time. It is worth mentioning in this regard, the first genetic studies on twin sibling (Folstein and Rutter 1977a, 1977b) suggesting high genetic liability of autism, as well as the first study on autism epidemiology in the UK carried out in 1979 (Wing and Gould 1979). Psychiatric thinking about autism changed dramatically. In 1979, the *Journal of Autism and Childhood Schizophrenia* changed its name to *Journal of Autism and Developmental Disorders*, and one year later the DSM III finally included "infantile autism" within the broader category of Pervasive Developmental Disorders. As autism persisted also in adulthood, in 1987 the DSM III-R replaced "infantile autism" with the broader term of "autism disorder". In the late 80s, Lorna Wing - an English child psychiatrist and mother of an autistic girl - suggested a continuum of autistic conditions by developing the broader concept of "spectrum" (Wing 1988). Further studies on autism's comorbidity (Rutter et al. 1994), neural basis of language, cognitive and social skills' development (Wing 1997) began to spread and gain some influence.

Despite the spreading of these latest innovations regarding autism's nature, Portuguese mental health professionals were yet very critical about the organicist thinking: their psychoanalytic positioning was still firmly prominent. As a result, the mother-child relationship remained at the core of psychiatrists' concern also from the late 60s till late 90s and was associated with other aspects of the child's life. For instance, low schooling performance was attributed to likely

serious lack of affection, which can be compensated by “a valid mother’s substitute (Ataíde 1968a:40). Similarly, a child’s disability was supposed to profoundly influence mother-child relationships insofar as “guilty feelings turn mother extremely permissive or if she is unable to bear guilt she started to unconsciously reject the child” (dos Santos and de Sá 1970:244). Child psychiatry attributed to the mother-child relationship a so deep and paramount influence that the before mentioned “Manual of Child and Adolescent Psychiatry” referred also to the “affective conflicts of the mother and emotional experiences of the foetus”:

“From her conception, the individual is subjected to the action of both external and maternal environment (...) Mother’s involvement in emotionally-intense situations (...) can cause to the foetus an emotional “trauma” because the chemical alteration derived from the emotional reaction could alter the level of blood irrigation - due to an increased release of adrenaline in the blood - and the proper balance of the amniotic fluid where the foetus is immersed” (Ataíde et al. 1977:189).

Also, child’s postural and motor instability suggested a sense of insecurity and tension due to parental anxiety and depression (dos Santos 1988). During the 90s, Gonçalves (1992) supported the correlation between parents’ intellectualism and autism’s insurgency by stating that parents who attained high levels of education and strongly committed to their careers were likely to have children late in life and “were not ready” to develop an emotional bond with their children. The author argued how late maternities are especially “experienced by mothers with guilt, causing depressive feelings and avoidant behaviours towards their infants” (idem:105). Home and family environment were likely thought to promote emotional issues also in children with hyperactivity (Leonardo 1998:54) as well as their “motor restlessness”, which resulted from maternal insecurity, anxiety and/or depression (Salgueiro 1996).

Since family’s emotional and relational environment was thought to play a role in the aetiology of child’s psychopathology, psychiatrists recognised the value of involving both children and parents in their intervention. According to Delgado (2008), psychodynamic psychotherapy in children began in 1909 when Freud explored the use of play therapy, formally introduced by Hug-Hellmuth in 1921. Later, Anna Freud and Melanie Klein, by acknowledging child’s play symbolic and unconscious meaning, outlined the technique and eventually pioneered the study of the biopsychosocial developmental stages of the child (idem:68). As I described in Chapter I regarding child psychiatry practice at Julio de Matos’ infantile pavilions and at outpatient

services of the CSMIL, the most part of children with so-called “autistic psychoses” were treated with psychodynamic techniques such as play therapy, maternage, psychomotricity and psycho-pedagogical support (Vidigal and Guapo 1997:208). Mental health professionals also used “techniques of physical contact, in which the body of the female psychotherapist usually represents the maternal body” and positive or negative reinforcement techniques, such as satisfying foods, isolation and darkness, to stimulate autistic children’s interest in social relationships (Ataíde 1968b:25–26). Mother-child psychotherapy still represented an “indispensable complement of a psychological prophylaxis in order to avoid [mother’s] guilt or hostility towards the psychotic child” (Ataíde 1969:47) while a marginal use of psychotropic drugs (such as Lysergic acid diethylamide) aimed at reducing “anxiety and autism symptoms” and at improving children’s social inclusion (idem:48). The role of therapists (psychiatrists, psychologist, educators) and of their ability to create an attachment with the child, as well as a collaboration with the parent, was of great importance. According to Gonçalves (1992), the therapist is in charge of taking care of the autistic child by creating an emotional bond with her and by helping mothers to “get acquainted with this ‘new’ child who looks like a stranger to her” (idem:99). At this regard, the patient-therapist relationship was thought as particularly challenging, because of autistic children’s tendency “to ignore the other as a human being and as someone who has an inner life, a psychic space as well as an affectivity” (Marques 1998:8).

The remarkable impact of the tenets and teachings of psychoanalysis on Portuguese child psychiatry produced a body of knowledge whose influence is still diffuse. The first generation of pupils of João dos Santos strongly advocated the impact of the mother-child relationship on the child’s affective development and likely psychic conflicts that could lead to inter-subjective issues. Until the late 1990s, the therapeutic work is still centred on the family - the core of preventive health care for dos Santos himself (dos Santos 1969:142). Indeed health care workers investigated the family network to understand the place occupied by the child as well as the effects that her disorders could have on it (Vidigal and Guapo 1997:208). Care and promotion of child mental health were tangled with adult mental health’s prevention and with child psychiatry’s moral aspiration to construct a better society by focusing on children at risk. On one hand, the surveillance on children unravel the ways in which they are categorised as normal or at-risk. On the other, by problematizing children’s developmental conditions it also extended the power of the social and medical gaze as well as its network of visibility (Tseng 2016:114). As childhood’s perils and difficulties require an expert guidance, child psychiatry is called to intervene and supervise children susceptibility to mental disorders: “children come

seeking the mental health team from dismembered and diseased families, from a troubled and confused school. And what do they ask? (...) they ask the child psychiatrist: to adapt, to normalize, to put things in order” (Fialho 1992:47).

The child psychiatry’s literature of second-half of the 20th century reveals also a comprehensive view of new neurobiological investigations about autism disorder and thus the need to reorganize therapeutic programs. Indeed, after the 80s psychotherapeutic treatments gradually lost ground to psychopharmacology and behavioural therapies (Delgado 2008). The spread and reinforcement of cognitive and biological approaches to autism forced psychoanalytic-oriented child psychiatry to take into account its likely neurological and genetic determinants and to adopt a broader range of diagnostic techniques (such as cerebral radiography EEG, nuclear magnetic resonance, clinical and electrophysiological examinations of hearing and vision, blood and urine biochemical tests, genetic tests). In France and Portugal, where psychoanalysis enjoyed a greater consideration, psychotherapies have been considered as inadequate to encompass social as well as cognitive development in autistic individuals. Nevertheless, in the 90s Portuguese child psychiatry acknowledged itself as a discipline “under the aegis of psychoanalysis” (Salgueiro 1992:25) and accused behaviourism to be a reductionist form of social conditioning that does not address root causes (idem:28). The complexity of the range of symptoms, skills and levels of disability that occurred in autism spectrum disorders and its aetiological uncertainty contributed to sharpen the controversy between the different therapeutical schools of thought. Some Portuguese child psychiatrists accused biological psychiatry to “condemn and even contraindicate psychotherapies” (Vidigal and Guapo 1997:209) based on the false allegation that psychoanalysts still support the psychogenic theory of autism.

A 2003 book entitled *Eu sinto um tormento com a ideia do fim definitivo: uma viagem ao mundo do autismo e das psicoses precoces* (I feel anguished with the idea of a definitive end: a journey into the world of autism and early psychoses) still associates autism to early infantile psychoses (Vidigal and Guapo 2003). Similarly, a 2011 book *Por detrás do espelho: reflexões sobre o mundo desconhecido da criança autista* (Behind the mirror: reflections on the unknown world of the autistic child) reiterates the image of the autistic child as hidden in a shell and trapped in her own world (Vidigal and Bilreiro 2011). Both titles use spatial metaphors to talk about autism. Their authors embark on a journey to “go inside” autistic children’s world (that is, their mind), a world extremely distant and closed in itself (like a mirror), an exotic and weird country

rarely visited by outsiders - the autistic child is inside while our world is kept “out”. I have also witnessed the contemporary dynamism of this view during the 2015 meeting “Contemporary Challenges of Clinical Psychology” organized by the Department of Clinical Psychology of ISPA (Lisbon’s Institute of Applied Psychology). At 11h30 I was waiting for the session “Autism: nature vs nurture”. Dr. Salgueiro, a psychoanalyst and child psychiatrist mainly known for his work on children with ADHD, begin his lecture by underlining the importance of the psychoanalytical method in the clinical approach to autism. The available neuroscientific and genetic findings have not given, according to the author, more scientific value to psychology’s understanding of childhood disorders. He further stated indeed that despite some psychological conditions as autism may derive from neuron dysfunction, brain and neurons do not explain the suffering that human beings experience. Afterwards, Prof. Aleixo, a clinical psychology professor, introduced his topic on schizophrenia and “autism psychosis” describing both of them as the most challenging childhood psychoses because of their variability. By reporting his own clinical experience, he argued how psychological work should necessarily involve verbal communication, which in the case of autism is severely compromised because of the “collapse of the symbolic thought”. According to him, indeed, the lack of self-awareness represents the most problematic issue in early childhood psychoses. I was not surprised then when he stated that this lack or dramatic alteration of self-consciousness results from a dysfunction in the mother-child relationship. While genetics and neuroscientific research may confirm to him child’s initial susceptibility or fragility, there are eventually dysfunctional intersubjective relationships that lead to the appearance of a psychosis: the emotional and relational environment has indeed a strong influence on child development as it can alter the child’s neural structure. As a result, while preventive strategies can be maximally effective during prenatal and early childhood stages, the most effective treatment once the psychosis emerges is the analytical one, because it intervenes in the relationship: “there is no other way except psychotherapy” he concluded.

The roots of Portuguese autism advocacy

So far, I tried to show how the historical roots of Portuguese child psychiatry explain the persistence of psychoanalytic lexicon till nowadays. Part of the medical establishment continues to believe in the validity of psychiatry and psychoanalysis for autism treatment - long after the rest of the world has switched to alternative methods. In this section, I will illustrate the birth of the first parent-led autism association created in Portugal and show the role it played in favour a biological explanation of autism at the expense of psychoanalytic view. I will also

underline how the emergence of mental health groups and movements is a phenomenon that aroused following different events: the process of deinstitutionalization of psychiatric services, the growing responsibility assumed by families in the creation mutual aid and support networks following the absence of a proper welfare state, as well as the increasing impact of genetic and neurological research on autism understanding. Before addressing these issues, it is worth clarifying how a so-called “disabled people movement” usually refers to the activities and networks created by organisations of disabled people, that is, those in which “at least 50 percent of the management committee or controlling body must, themselves, be disabled” (Oliver 1990:113). The definition of “disability movement”, instead, includes also organisations devoted to disabled people and led by non-disabled people. Despite my fieldwork addresses autism advocacy by focusing on groups led by parents of people diagnosed with ASDs, I will briefly report the history of the Disabled People Movement in Portugal in order to better comprehend the broader context of autism advocacy.

Disabled People Movement in Portugal

According to Portuguese sociologist Fontes (2014), during the Estado Novo dictatorship (1933-1974) disabled people experienced physical, cultural and social barriers and did not benefit from regulations nor specialist services. These factors resulted in the relegation of disabled persons to the margin of society and led to social exclusion, poor health conditions and high rates of poverty. The negative impact of these trends seriously hindered disabled people’s participation in society and forced them to rely on family and friendship networks and on few private Catholic charities. At this regard, the first charitable organisations for deaf and blind people - dating back to the 1920s-30s - were “tolerated by the political regime because [they] functioned as peer meetings and/or sports groups, thus reinforcing the social isolation of disabled people”. None of these collectives, indeed, “developed any political understanding of disability or were involved in any type of public or political intervention” but rather replaced State’s responsibility for a large part of its society. The first specific-impairment and volunteer-run organisations promoted by parents of disabled children and health professionals in the mid-20th century were still inspired by a charity and philanthropic purposes (idem:1400).

The regime’s control over civil society prevented the development of any form of political activity or social movements until the fall of the dictatorship in 1974 (Fontes, Martins, and Hespanha 2014:7). The revolutionary climate and the lifting of legal constraints on collective action encouraged the creation of grassroots initiatives. The Portuguese Disabled People’s

Movement, for instance, emerged thanks to the re-establishment of a democratic regime and to the return to Portugal of a huge number of young impaired military personnel from the colonial war in Africa (1961-1974). In particular, the creation of the *Associação Portuguesa de Deficientes* (Portuguese Association of the Disabled) in 1972 and the *Associação dos Deficientes das Forças Armadas* (Association of the Disabled of the Armed Forces) in 1974 resulted from the mobilisation of veterans disabled (Fontes 2014:1401), who finally denounced the political, social and economic exclusion they experienced and claimed for the provision of services and supports. Despite some improvements, the Portuguese Disabled People's Movement was characterized by (i) the absence of a shared ethos that increased the movement's fragmentation and prevented the formation of a collective identity, (ii) the hegemony of a medical model of disability that, by defining disability as a medical issue related to the individual body, perpetuated the idea of disabled people as passive subjects dependent on rehabilitation and welfare benefits as measures to compensate their body's deficits, and thus (iii) failed to give attention to the ways in which a disabling society rather than individual impairments contributed to the exclusion of disabled people from everyday social life (idem:1405).

Besides suffering from discrimination, prejudice and ignorance, disabled persons saw their rights threatened by the lack of welfare programs. At this regard, while after World War II the welfare state became the ideal model for many European states, in Portugal we assist to the creation of what Boaventura de Sousa Santos defined a "semi-welfare state" (Santos 1993). This appeared only after 1974 when this model of social protection was already in crisis (Fontes et al. 2014:8) and the post-regime governments were facing great economic and social problems, such as inflation, unemployment, falling wages, poverty and the huge return of Portuguese settlers from Africa. To a large extent, the low level of political participation amongst disabled people and the consequent lack of politicisation of disability issues in Portugal was thus due to disability organisations' dependency on the State - which prevented disabled people not only to take part in society but also to influence the decision-making processes and activities concerning their own care and service development - and contributing to their economic fragility. Furthermore, the "affirmation of a benefits mentality in which disability mainly emerges as a charity issue has established a paternalistic logic that even today takes precedence over recognition of political and economic autonomy as a right that enriches the democratic arena" (idem:7).

After the revolutionary period (1974–1976), the Disabled movement entered into a “phase of institutionalisation or normalization” insofar as the creation in 1977 of the National Secretariat for Rehabilitation (SNR) and of the National Council for Rehabilitation have served the State for “pacify and control the movement” (Fontes 2014:1403-4). To reduce the costs of social exclusion and discrimination, most of the disability organisations provided services and access to benefits payments and did not use their human and financial resources for a broader political project of social change. The main aim of the Disabled People’s Movement was to achieve “first-level demands” which “focus on basic, everyday rights or the rights needed to achieve a minimum standard of citizenship” (ivi). Besides a lack of engagement with the social model of disability and of political understanding of disability issue, in Portugal “activism never totally embraced the social model of disability” because of “the frailty and incongruence of the social and political citizenship project” (idem:1402). Despite its weaknesses, all over the years Portuguese Disabled People’s Movement forced the State to recognise disabled people’s rights and its own accountability for the development of disability policies (Fontes 2011). By doing so, the movement succeeded to turn 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” (Fontes 2014:1407). As soon as the role of the movement gained importance, disabled people increasingly denounced situations of social exclusion and oppression, demanding rights and challenging dominant and disabling understandings of disability.

Today, despite some considerable progress, disabled people are still experiencing disadvantage and discrimination. The low commitment of the state and the inability of civil society to change the social inequalities that disabled people face represent a fragility that translates into a “systematic lack of coherent legislative change” (Fontes et al 2014:8). As a consequence, disabled people keep living on inadequate social benefits and struggling with the education system and a labour market “that excludes difference” (Fontes 2014:1408). As a result, Portuguese academic environment is nowadays facing four main issues:

the absence of a scientific community with a solid grounding in disability studies; the economic vulnerability and social marginalisation that hamper the social participation of disabled people; the authoritarian trappings of a state that isolates disabled people’s organisations from decisions that concern them; and the weaknesses of the Portuguese welfare state, which frequently means that disabled people’s organisations use up all of their resources on providing services (idem:11)

The deinstitutionalization movement and the State's paralysis

In the '60s, an important mental health policy indirectly marked autism history: the widespread replacement of long-stay psychiatric hospitals with community-based mental health services targeted for patients diagnosed with a mental disorder or disability (Hollin 2014:100). Several scholars have, indeed, denounced the repressive nature of the institution of the asylum and the disciplinary role of psychiatry itself (Foucault 1963, 1965) resulting in the social exclusion and discrimination of patients (Goffman 1961) and in the normalization and control of social deviance (Szasz 1974, 1984). The reorganization of psychiatric care system and its transition to community-based health care services first aimed at avoiding the negative effects of long-term hospitalization and confinement. In Europe, the anti-psychiatric movement, the reform of mental health social policies, as well as technological advancement such as the advent of psychotropic drugs, contribute to promote a humanization of psychiatric treatments and to implement individuals' autonomy and social inclusion. Furthermore, and with respect to my object of research, the deinstitutionalization of mental retardation and disability (Eyal et al. 2010:3) has also implemented childhood surveillance and protection "as it became paramount to demarcate the mental problems and needs of children and adults who had previously been confined but were now being integrated into the population" (Evans 2013:11).

In Portugal, unlike other European countries, the first mental health reform occurred only during the second half of the 20th century (Bragança 2013; Filho et al. 2015; Hespanha 2010). However, already in the early 1960s, mental health professionals have expressed their criticism towards long-term psychiatric institutionalization, denouncing patients' living conditions inside the Julio de Matos psychiatric hospital (Chapter I). The first legislative resolution in 1963 (*Lei de Saúde Mental n° 2118, 1963*) established the development of out-patient mental health facilities in order to ensure a broader access and continuity to psychiatric care and to improve patients' inclusion in their community (Filho et al. 2015:118). Despite these efforts, Portuguese anti-psychiatric movement did not achieve the expected results. According to Hespanha (2010), the decentralization of hospital care did not really translate into a transition to community care mainly because of the scarce reception and influence that medical and socio-political thinking of Franco Basaglia had in the country (Hespanha 2010:139). Instead, Portugal followed a different model of reorganization of mental health services policy initially ideated in France in the mid-1940s and eventually implemented in the 1960s called *Psychiatrie de secteur*. This established that each geographical area would be provided with its own outpatient psychiatric services led by a multidisciplinary team (doctors, social workers, psychologists, nurses). The

sectoral model contributed to the reform of institutional psychiatry and reduced patient's hospitalization only for acute or painful crises. However, it failed to create a network with patient's family and her broader social environment due to practical difficulties (such as shortage of staff, administrative slowness and lack of funding) but also and above all for "the resistance of the psychiatrist to abandon his/her own institutional defences and meet the patient in her living environment" (Vigorelli and Traini 2005:82). The anti-psychiatric ideology of Franco Basaglia had, on the contrary, both medical and socio-political purposes. On one hand, the asylum was by its very nature unable to cure the patient, contributing rather to worsening her condition (Basaglia 1968). Influenced by Goffman's work *Asylums* (1961), Basaglia "saw people inside the 'total institution' of the asylum as having been reduced to 'non-persons' or 'hollow men'" (Foot 2014:238). On the other hand, the closure of psychiatric institutions should have foreseen a rethinking of social deviance in order to avoid the idea of ghettoization as a desirable social measure (Basaglia and Ongaro Basaglia 1971)²⁶.

The Portuguese authoritarian regime, spanning more than four decades, also contributed to the delay in the implementation of psychiatric care reform. The transition to a democratic regime occurred only in the mid-1970s when society experienced a profound and rapid process of social change. Facing serious economic deficiencies, a 1984 administrative measure (*Decreto-Lei n° 74*) attempted to launch community psychiatry, by including mental health services into primary health care (Filho et al. 2015:120). Eventually, a 1992 law (*Decreto-Lei n°127*) established the closing of mental health centres and mental health centres for children and adolescents by integrating them into the district general hospitals (Siqueira-Silva, Nunes, and Moraes 2013:482). Many mental health professionals viewed the integration of child psychiatric facilities into paediatric hospitals' departments as a way to reinforce the centralized power of general hospital. According to Vidigal et al. (1999), the centralism required by the hospital administrations meant not only the loss of administrative and financial autonomy of the psychiatric services but represented also an attack of the value and autonomy of the multidisciplinary team-approach of child psychiatry (idem:164-7). On the contrary, Alves (2011) considered the 1992 law of psychiatric reform as a strategy able to diminish the segregation of mental health specialized services and read Portuguese psychiatry's criticism as a "resistance" towards the deinstitutionalization process, insofar as "the class that challenged

²⁶ The "social confinement" of the psychiatric patient was indeed considered by Basaglia as a measure necessary for the capitalist system in order to maintain social order and eliminate human inefficiency within the working system.

this integration accepted, however, that the great psychiatric hospitals continued to exist” (Alves 2011:51). Despite the international recommendations, the adoption of the philosophy of community-centred psychiatry failed because of an ongoing system of “missed connections” between what is legally defined and what it is actually practices that “permeate Portuguese Mental Health Policy and reveal the tolerance of the State to corporate interests” (Siqueira-Silva et al. 2013:483).

In 1994, the creation of an interministerial committee called CESM (*Comissão de Estudos da Saúde Mental* - Committee for the Study of Mental Health) aimed at shaping future mental health guidelines by implementing the deinstitutionalization of psychiatric services and providing community approach and continuity in outpatient care (Filho et al. 2015:122). A new legislative measure in 1998 (*Lei de Saúde Mental n° 36*) eventually established the decentralization of hospital services and the creation of a diversified network of community services (Siqueira-Silva et al. 2013:486). The first census of long-term psychiatric patients hospitalized in public and private facilities and wards is carried out only in 2001, the same year that the CESM eventually announced the closing of the Psychiatric Hospital Miguel Bombarda. In Portugal, the transition to community psychiatric care has been a complex and problematic issue that affected - clinically, socially and politically - people with psychiatric diagnoses even in recent time. Despite the willingness to provide public psychiatric care and implement patients’ social inclusion, mental health policies have not been fully able to achieve their aims because of the scarcity of financial resources and of rehabilitation units, as well as of the inadequacy of socio-occupational programs and residential facilities for psychiatric patients (Palha and Palha 2016).

The lack of enforcement of health legislation and the consequent “erratic process of deinstitutionalization” (Hespanha 2010:139) ended up by forcing patients and their families to affiliate in order to guarantee care and the provision of support services that the State was unable to provide (Alves and Silva 2002). By the mid-20th century, “a new volunteer-run, specific-impairment organisations sector emerged fostered by parents of disabled children and professionals” (Fontes 2014:1400). These associations mainly appeared as a way to fill public health sector’s gaps and the State’s lack of intervention (Nogueira and Portugal 2010:31). They looked, indeed, for solutions at the community level by providing a wide range of activities such as family psychological support, home visiting programs, legal counselling, and services targeted to patients such as vocational training, job placement and follow-up in the labour

market, socio-occupational reintegration programmes and community residences. The inability of these associations to generate sources of self-financing turned them dependent on cooperation agreements with the State and donations so that this scarce resource allocation plan threaten their continuity and resulted in limited interventions (idem:34). Before the collapse of the dictatorship in 1974, Portugal had not yet developed a welfare state but a “system of compulsory social insurance” that excluded those citizens unable to access the labour market, such as disabled people (Fontes 2014:1400). As a result, those who fell outside the protection system depended on kinship and friendship networks and on few private or religious charitable organisations, whose initiatives were nevertheless under the State’s control. Created in 1979, the Portuguese welfare state “soon turned into a selective system, introducing a contributory and non-contributory regime with different levels of provision” (idem:1402). The efforts put by the families to replace and compensate the void of the public social security system (Alves and Silva 2004; Hespanha 1999) with regards to health care services and social support reinforced disabled people’s dependence on family, showing the challenges of deinstitutionalization in the country (Hespanha et al. 2012). As argued by Alves (2010), Portugal has actually “trans-institutionalized” people diagnosed with mental disorders and disabilities within the family:

“the State used families as a resource for implementing the de-institutionalization and community psychiatry, as surrogates for out-patients structures, and not as partners of a therapeutic and rehabilitative strategy. There is no dialogue, nor exchange, but a transfer of guardianship” (idem:41).

The Portuguese feral child: the case of Isabel

At the burst of the 1974 Revolution, Portugal endured nearly 50 years of political subjugation, a conservative social set-up, and economic problems. There was neither a national network of mental health facilities nor a policy framework able to provide support and services to children with mental disorders and disabilities. Under these circumstances, the so-called “handicapped” or “abnormal” children were often kept at home living in poor conditions or abandoned.

On this respect, the local newspaper *Diário de Notícias* (19th January of 1980) published in 1980 a reportage investigating the case of abandoned children, revealing the existence of a 9-year-old girl named Isabel, whose mother had shut her inside a chicken coop for eight years and fed only with corn, cabbages and coffee (Castilho 2013). The case was sadly titled under

the name of “The Chicken Girl” (*Menina Galinha*). First clinical observations revealed Isabel’s extremely aggressive attitudes, a profound mental retardation, bone underdevelopment and “a face similar to the gallinaceous (her profile, lip position, and dentition looked as if she had a beak), large eyes, calluses on her hands, chicken wings-alike position of the arms, and a cataract certainly due to a chicken’s bite” (Margarida 2008). Isabel was, first of all, a victim of maltreatment and neglect. She never received a healthy diet nor proper hygienic conditions and suffered from a severe deprivation of basic human needs living in a family environment characterized by extreme poverty, illiteracy and promiscuity (her father was seemingly the brother-in-law of her mother). Taken to the court, Isabel’s mother lost her parental rights. A religious organization called “Alpha Movement” first attempted to hospitalize Isabel until finding a suitable host institution (Oliveira 2004). Meanwhile, a radiologist working at the hospital succeeded to host the child at her home but for only 15 days: “I was creating many enemies - she said to journalists - and I was even professionally harassed because of my decision”. A re-education institution, called *Colégio Ocupacional Luís Rodrigues*, in Lisbon, finally admitted her (idem). In 1998, an article titled *Menina galinha - 18 anos depois* (Diário de Notícias, 14.11.1998) reported how Isabel was eventually living inside a religious institution in Fatima. Despite showing less aggressive behaviours, she was still suffering from back pain and was unable to walk properly and to hold fine motor skills (she was barely able to eat with a spoon). She could only mumble a few words and she seemed able to decipher and perform some emotional facial expressions, showing some social skills and a better control over her own emotions. João dos Santos commented the case by arguing how:

“a human environment that does not provide a child with physical contact - from skin to skin, from a body to another body, from gesture to gesture - did not facilitate nor promote the language. The language implies the existence of people who speak and express themselves, and it also implies a physical contact, which this child (Isabel) doesn’t have. De facto she behaves as wild children” (Castilho 2013)

dos Santos compared the case of Isabel to the famous French case of Victor of Aveyron, the “feral child”. Victor’s case was taken up in 1800 by French physician Jean Itard who worked with the boy for five years. Itard believed that empathy and language separated humans from animals. Accordingly, he wanted to forcibly “civilize” Victor by teaching him to speak and to communicate human emotion. Although his work with Victor was not entirely successful, Itard was one of the first to attempt the education of mentally retarded children and to claim about

the importance of early exposure to the language. Several artistic works fictionalized Victor's life, such as a 1970 film *L'Enfant Sauvage* (The Wild Boy) by François Truffaut, as well as a 2003 novel "Wild Boy" by Jill Dawson and in one novella of the 2010 collection "Wild Child and Other Stories" by T. C. Boyle. The term "feral" or "wild" child was not a diagnostic category but rather a label used to refer to children who were supposedly living in the wild having been reared by wolves or other wild animals. Wild children were usually described as lost, stolen or abandoned infants grown up with minimal or no human contact and then discovered or captured by chance. Therefore, they were considered as living examples of a supposed zero degree of human development, showing the dramatic impact of emotional and human deprivation.

Most historical accounts describe feral children as displaying animal-like behaviours: they ate only raw foods, they were mute and insensitive to cold, and they usually walk on all fours. In an article titled "Feral Children and Autistic Children", Bettelheim (1959) first argued that, despite there was no sound evidence of animal foster-parents, the behaviour of the feral children strongly resembled that of severe cases of infantile autism:

"Study of the so-called feral children and comparison of them with known and well-observed wild autistic children suggests strongly that their behaviour is due in large part, if not entirely, to extreme emotional isolation combined with experiences which they interpreted as threatening them with utter destruction. It seems to be the result of some persons' - usually their parents - inhumanity and not the result, as was assumed, of animals' - particularly, wolves - humanity. To put it differently, feral children seem to be produced not when wolves behave like mothers but when mothers behave like non-humans. The conclusion tentatively forced on us is that, while there are no feral children, there are some very rare examples of feral mothers, of human beings who become feral to one of their children" (idem:467).

The reference to supposed mothers' "feral attitudes" towards their children sounds now extreme violent, underserved and misogynous. Many years later, several scholars speculated that so-called feral children could have been diagnosed with developmental and mental disabilities, cognitive delay, and even autism (Wolff 2004). For instance, autism experts Lorna and John Wing and Uta Frith (Frith 1989; Wing and Wing 1976) acknowledged Victor as one of the first documented cases of infantile autism. In the book "*L'énigme des enfants-loups*" (The Mystery of the Wolf-Children), French surgeon Aroles (2007) also argued how Victor's behaviours

showed point to a mild “degree” of autism (idem:211-12).

Stories about feral children reveal extreme cases of neglect, isolation and lack of socialisation and show the impact that these have on child’s cognitive, social and emotional development. They also unveil how children with learning and intellectual disabilities as well as children showing different paths of development were often abused or abandoned. The *Menina Galinha* case sadly revealed the existence of a grey zone in children’s healthcare and protection even at the end of the 20th century. The struggles and commitment of both health professionals and parents of disabled people eventually managed to overcome this void through the creation of a network of associations working to ensure children are protected in their rights. For instance, in 1975, there already existed the Portuguese League of Physically Disabled, the Portuguese Association of Parents and Friends of Mentally Disabled Children, as well as the CERCIS, a Disabled Citizens Education and Rehabilitation Cooperative.

Re-think autism: for a biological conception of the disorder

The first Portuguese grassroots autism organization was created at the initiative of José Carlos de Almeida Gonçalves, a dermatologist specialized in venereology working at the Lisbon Leprosy Institute and father of an autistic boy. Dr. Gonçalves contributed to the spread of international literature related to autism in Portugal and his son Luis is acknowledged to be the “first autistic child” diagnosed in the country (Raimundo 2011; Ribeiro 2012). While in the next paragraph I will explore in more detail his role in the creation of the first Portuguese autism advocacy association, in what follows I will investigate his own autism-related scientific production and how it contributed to the acknowledgement of the modern biological conception of autism disorder. The importance of Dr. Gonçalves’ figure relied, indeed, on his position within the intellectual environment of that time but also on the role and influence he played in the birth of Portuguese autism advocacy movement. As a matter of fact, some of the first and most renowned autism advocates were not only parents of autistic children but also health professionals (Dr. Gonçalves’ wife was a psychiatrist). For instance, Lorna Wing - a psychiatrist and pioneer of childhood developmental disorders’ studies - had an autistic daughter and was involved in the creation of the National Autistic Society (NAS) in the UK. Similarly, Bernard Rimland, a psychologist and father of an autistic son, was the director of the Autism Research Institute in the USA and founder of the Autism Society of America.

I will show, in particular, how the two article Dr. Gonçalves (1971b, 1972) published in the *Revista Portuguesa para o Estudo da Deficiência Mental* clearly advocated for a change in the articulation of autism conception.

First, Gonçalves recognized a “probably genetic” aetiology of autism (Gonçalves 1971b:367), as well as the presence of neural differences in the anatomy, function, and connectivity of different brain regions. Among the common autism’s traits (such as the insistence on routine and resistance to change, or deficits in basic self-awareness), he also mentioned the presence of significant sensory-perceptual alterations, which he described as primary symptoms with respect to social and emotional issues. He, thereby, supported the idea that autistic children’s isolation was a secondary reaction to altered sensory processing that impacted their social functioning. These alterations in auditory perception lead to different ways of categorization, codification and storage of auditory information and explained why autistic children cannot bear some noises while tirelessly elicit some others. In a similar way, he argued how gaze avoidance might be a way of managing the cognitive load associated with the processing of visual environmental information and did not correspond to a refuse of human contact. For instance, autistic children used peripheral vision rather than looking straight at an object or to a person because of a difficulty of grasp the information coming from the central part of the retina (idem:369).

Secondly, Gonçalves’ reference to autism studies and researches at the Maudsley Hospital Psychotic Clinic for Children in London (Gonçalves 1972) is particularly relevant not only because it shows his connections with English researchers but also the growing influence of a biological understanding of autism. Gonçalves’ conception of autism aroused from autism studies carried out by child psychiatrists team working at the Maudsley Hospital. According to Evans (2014), this institution was central in driving broader shifts in the conceptualization and treatment of children with psychiatric problems in the UK (idem:256), as well as in changing autism understanding and in establishing a field of autism research (idem:258). According to the author, UK legislative changes during the 1950s and 1960s forced to re-think the way children should have been evaluated and classified as well as the way their rights should have been protected. The 1959 Mental Health Act, for instance, placed for the first time those children previously designated as “mentally deficient”, “uneducable”, “psychotics with autistic traits” or “schizophrenics” into a broader category termed “in need of care” (idem:272–75). This occurrence refashioned the organization of hospital and educational care and contributed

to establish and shape autism as a legal category in the UK. While early 20th-century surveillance medicine has already lead child population to the attention of local authorities, social workers and health professionals (Chapter I), the production of new methods and procedures for the detection of psychological growth increased the control on child developmental. In this regard, Anglo-American child psychiatry introduced the use of epidemiological studies of mental disorders in children and adolescents rather than keep basing its clinical observations on case-studies method. The introduction of epidemiological studies in child psychiatry during the 1960s provided the concept of autism with a new framework (Eyal et al. 2010; Feinstein 2010). Evans additionally found that following the wake of the 1959 Mental Health Act, the “Social Psychiatry Research Unit” at the Maudsley Hospital “became a world-leading centre for epidemiological and statistical research in mental health, in particular relating to schizophrenia and autism” (Evans 2013:13). The growth of epidemiological and statistical studies during the 1960s and 1970s directly affected the meaning of autism for the Anglo-American world. In particular, the reproducibility of these studies required the development of an adequate language and behavioural description for autism detection, which enabled Maudsley Hospital researchers such as Victor Lotter, John Wing and Michael Rutter to eventually design and conduct “the first mass survey of an entire population cohort in order to generate a percentage figure for the rate of autism in the general population of Britain” (idem:15). In more broader terms, autism epidemiological studies helped also researchers to address wider questions about the development of infantile thought and development:

“Autism has always referred to the most severe pathology in infantile thought and changes in its meaning reflect broader historical changes in what is considered abnormal in the thought and behaviour of all infants and children. These central abnormalities are now framed by new language concerning cognitive abilities and deficits which were not considered relevant when autism was related purely to psychopathology rather than learning disabilities as well” (idem:26).

A third and broader reason of Gonçalves’ relevance in autism field lies in his connections with the international scientific elite of his time. Although small, his scientific production testifies how during the ‘70s autism was passing through a paramount epistemological change thanks to a network of outstanding researchers recognized at international level. Belonging to the Portuguese intellectual environment, Gonçalves was acquainted with both national and international scientific community. He contributed, for instance, to the spread of Rimland and

Wing's comparative studies on autism (Rimland 1971; Wing 1969), as well as of Rutter and Folstein's pioneering studies on autism genetics (Folstein and Rutter 1977a, 1977b). Later work by Rutter (1978) led to autism diagnostic criteria structured around three core areas of the deficit: social impairment, communication difficulties, and rigid and repetitive interests and activities. DSM III will define infantile autism largely according to Rutter's so-called "autistic triad" of impairments until the until the concept of "autistic spectrum" became known (Wing 1996). The centrality of these studies on autism's social and language impairments reflected psychology and psychiatry's growing interest in the cognitive aspects of mental disorders. This interest will eventually lead in the mid-80s to the spread of different cognitive theories of autism according to which some of the core elements of autism might arise from a primary cognitive deficit (Rajendran and Mitchell 2007:225).

Dr. Gonçalves' personal concern, familiar commitment and intellectual connections with the Anglophone child psychiatry contributed to spread autism biological view in the country²⁷. Gonçalves knew, for instance, that English researchers' new articulation of autism - understood as a syndrome caused by primary sensory-perceptual deficits, which arouse secondary affective and behavioural symptoms - could not be yet widely accepted. Portuguese mental health professionals argued that autism's emotional and behavioural traits were too serious to be merely the result of sensory-perceptual or cognitive alterations (Gonçalves 1971b:370). As a result, while in the UK autism treatment is fundamentally based on teaching methods, Portuguese "psychotherapists do not accept this interpretation and direct their efforts to overcome supposed inhibitions or environmental toxic causes to which they attribute determinant etiological importance" (idem:371). Gonçalves' considerations reveal, thus, the ongoing debate regarding concurrent conceptions and approaches to autism. In this regard, he published his papers in a journal where other authors, especially child psychiatrists, kept referring to autistic children as "psychotic children". On one hand, this reveals how part of the scientific community was still endorsing the assumption that autism was a psychosis caused by psychological factors. On the other hand, it also unveils how the dissemination of a biological view of autism enjoyed the favour of part of the scientific environment. Overall, this analysis shows the vitality of autism research which at the time was already a dynamic area of scientific endeavour that attracted many impressive scholars.

²⁷ Some psychologists, such as Evelina Bustorff, succeeded to arrange an exchange of correspondence with the National Autistic Society of Lorna Wing (Bustorff 1971:374).

Finally, Gonçalves' commitment to autism issues aimed at addressing the lack of adequate interventions and studies that could guarantee disabled children's rights. Alarmed by the social exclusion and abandonment of autistic children and their families (idem:368), Gonçalves wished for the development of structured pedagogical treatments attuned to the epistemological advancements of English child psychiatrists. Furthermore, he argued that "infantile autism" as a distinct condition was significantly underdiagnosed in Portugal and thus that more children had autism than was originally thought. Lotter's first epidemiological study of autistic children between the ages of 8 and 10 in Middlesex County in the UK (Lotter 1966) acknowledged and established autism as a distinct scientific, demographic, and social reality in Britain (Evans 2014:278). By comparing Lotter's autism prevalence rate, namely 4.5 per 10.000 children, Gonçalves estimated the presence in Portugal of about 700 autistic children between 5 and 14 years old and overall 3000 cases among children and adults (Gonçalves 1971b:367). An official epidemiological survey could have been used not only to direct further research investigation but also to design pivotal responses in autism treatment. Epidemiological studies, indeed, empower parents and communities to demand health services and rights, as well as to call Government to ensure that regulations and laws meet goals in improving and protecting health rights and reducing inequalities. They are, therefore, a fundamental prerequisite for turning autism into a public political issue. Despite Gonçalves' calling for immediate action, the first autism epidemiological study in Portugal will be eventually conducted only in 2007 (Oliveira et al. 2007). The survey targeted children born between 1990 and 1992, living in mainland Portugal or the Azores and attending elementary school (age 6–9) in the school-year 1999 to 2000. The authors estimated a global prevalence of ASD of 9.2 per 10000 cases in the mainland and of 15.6 per 10000 cases in the Azores (idem:729). According to them, a third of target population had not yet received an official diagnosis of ASDs, probably because - as they previously argued - "until the 1990s, ASD was seldom diagnosed in Portugal, and there was no specific policy on education or health provision for individuals with autism" (idem:728). To date, there are not newest data about autism prevalence in Portugal.

In the next paragraph, I will show how autism epistemological transformations are also deeply tangled with parents' advocacy practices. This interaction ultimately fabricated the autistic child not only as a statistical and psychiatric reality but also as a legal subject. The increasing prominence of childhood mental health and a new sensibility for disabled children's rights and needs converged to produce new understandings about the psychological and social development of children, as well as new practices in special care and education. The birth of

the first autism advocacy association allowed parents to organize as a community and to gather their efforts in order to campaign for the development, promotion and improvement of specialized services and treatments for children with autism. This resulted in a greater involvement of parents' in autism field not only as caregivers but also as promoters of their children's rights.

The birth of 1st Portuguese autism's parent-led association

During the second half of the 20th-century, disability rights movement gained momentum from the civil rights movement to secure equal opportunities and equal rights for all people with disabilities and prevent discrimination, abuse, neglect and other rights violations. As I briefly mentioned earlier, Dr. Gonçalves' role in advocacy movement aroused from his personal experience with his son, who is recognized as the first Portuguese child to have officially received a diagnosis of "infantile autism" (Raimundo 2011; Ribeiro 2012).

As reported in an interview that Gonçalves granted shortly before his death (Raimundo 2011), it was 1962 when his 2-year-old son Luís stopped talking and started showing symptoms of agitation and imbalance. Together with his wife Maria Helena Brotas - who was a psychiatrist - Gonçalves denied child psychiatrists' view and refused their invitation to undergo psychoanalysis sessions: "They (psychiatrists) told me that the child has nothing, that he was just a little bit nervous only. You parents, you are the sick ones, it's not the child". As I already explored in the previous paragraphs, during those years autism was conceived as a psychosis. Profoundly disappointed with Portuguese child psychiatrists of his time, Dr. Gonçalves eventually ask a retired psychologist Evelina Bustorff, who had long worked with disabled children in Germany, to care for his son. Thanks to a contact with an English bookstore, Gonçalves immersed himself in the study of child psychology and eventually find a likely diagnosis for his son in a book about non-verbal children: "early infantile autism" (Ribeiro 2012:30). Looking for an official diagnosis, Gonçalves sought medical advice to the NAS where Lorna Wing, who was already a well-known reference in autism's studies, eventually diagnosed his son with "early infantile autism".

Inspired by his own experience, he tried to help other parents who also had autistic children. As a result, he succeeded to invite a team of psychologists of the NAS in Portugal to provide medical training to both parents, teachers and health professionals, as well as to promote the creation of a school for autistic children, called the "Therapeutic Centre". Eventually, in 1971

he funded the APPCA - *Associação Portuguesa para a Proteção de Crianças Autistas* (Portuguese Association for the Protection of Autistic Children), which aimed at providing medical-pedagogical assistance to autistic children and at supporting their families' needs (Gonçalves 1971a:406). Gathering the collaborative efforts of parents, teachers, and mental professionals, Gonçalves wished that the association could eventually extend its activities all over the country in order to assist and account all people with autism. This first Portuguese parent-led autism advocacy association, indeed, played a crucial role in the lives of people with autism. Among the APPCA founding partners there was the person who would continue Gonçalves' project from 1984 - when the association is renamed APPDA - *Associação Portuguesa para as Perturbações do Desenvolvimento e Autismo* - to the present day: Dr. Isabel Cottinelli Telmo. Thanks to Gonçalves himself, her youngest son is also diagnosed with autism in England at the NAS. I eventually encountered and interviewed her in 2015. During our conversation, Dr. Cottinelli told me that João dos Santos himself was one of the doctors that Gonçalves unsuccessfully consulted. The times from then are now profoundly changed, but Gonçalves' legacy is still preciously guarded, as I will show in the next chapters.

Chapter III

Understanding autism: living with and caring for a child with autism

In this chapter, I will first describe my two parallel field sites (APPDA and online communities) and explain the process through which I gained access to them as a researcher. I will show, indeed, how autism advocacy is simultaneously “located” within the offline and online spaces that parents inhabit. As a result, face-to-face groups and online communities, which I acknowledge as deeply interconnected realities, represented the two places where autism advocacy is thought, constructed, and performed. I will then provide some ethnographic vignettes in order to introduce the different ways in which parents conceive themselves as advocates and report their different practices of advocacy.

Places and encounters

At the beginning of 2013, I started an exploratory fieldwork on Portuguese mutual support and advocacy groups led by parents of children diagnosed with autism. I first turned to the APPDA - *Associação Portuguesa para as Perturbações do Desenvolvimento e Autismo* (Portuguese Association for Developmental Disorders and Autism) since it represented the former APPCA, the first parent-led autism association founded in Lisbon in 1971 by a group of parents guided by Dr. Gonçalves (Chapter II). The APPDA-Lisboa currently represents the main autism association in Lisbon providing educational and therapeutic programmes for children with autism and support for their families. Some months later, I also started to explore several web-based advocacy communities such as Facebook parental groups as well as online forums and blogs.

Autism-advocacy sites

As I have described in chapter II, Dr. Gonçalves sought help for his own autistic child from the National Society for Autistic Children (NSAC, now called NSA - National Society for Autism) in London and personally encountered Dr Lorna Wing, one of the autism experts at the time. In order to sponsor novel educational and therapeutical models in Portugal, he asked a NSA team of researchers and mental health specialists to give professional and educational training to both Portuguese technicians and parents of the APPCA. The major objective of the APPCA

was to offer both educational and medical responses to autistic children's specific needs with the creation of a therapeutic centre and of a school with a special education program. Since during the 1980s it started to support also teenagers and adults with autism, in 1984 the acronym became APPDA - Portuguese Association for the Protection of the Disabled Autistic (*Associação Portuguesa para a Proteção aos Deficientes Autistas*). To spread its services to a broader population, the APPDA direction opened new regional centres in the northern part of the country (Coimbra, Viseu, and Leiria). In Lisbon, the APPDA was first located on the ground floor of a residential building in Campo de Ourique while in 1992, due to the need to support more users, the already APPDA moved to several prefabricated buildings in the neighbourhood of Restelo where it was also possible to build a Socio-Educational Support Centre (CASE - *Centro de Apoio Sócio Educacional*) and provide a range of different other services such as psychiatric consultations, educational training, and therapeutic support. Meanwhile, a first residential home is built in 1993 in Zambujal, a rural township about 20 kilometres away from Lisbon and in the same year the APPDA moved to a wider land of 12.000 m² located in the neighbourhood of Alto da Ajuda, at the foothills of the Monsanto, the largest green park of the city.

When I first moved to Lisbon to begin my PhD programme, I did not yet know that I was living at 20 minutes by walk from the APPDA. Two-story houses, some of which are provided with a small garden and sometimes a car parking, compose the neighbourhood of Alto de Ajuda, which quietness is sometimes interrupted by some bus or cars passing by the main street. The APPDA moved to this suburban area because of a donation of a wider property from the municipality of Lisbon, where later have been fabricated a day-care centre with a diagnostic clinic, a school of Special Education Needs (SEN – in Portuguese NEE, *Necessidades Educativas Especiais*), an Occupational Activities Centre (CAO), 4 residential units, as well as a greenhouse and a pool for therapeutic activities. Only in 2002, the APPDA structure was eventually decentralized and the several regional delegations were gathered into a national Portuguese Federation of Autism (FPDA) which has its headquarter in Lisbon, and the acronym APPDA came to mean Portuguese Association for Developmental Disorders and Autism. In January 2013, I eventually contacted the current director of the APPDA-Lisboa in order to have the approval to meet and interview some parents who attended the association.

Months later, in November 2013, I started to browse the activity of different discussion forums, blogs and Facebook pages related to autism in Portugal. Many autism advocacy groups led by

parents were indeed also internet-based communities with their own computer-mediated social interaction and practices (Wilson and Peterson 2002). This first exploratory phase allowed me to have a picture of the most *active* virtual groups. From March 2014, I created a “professional” account on Facebook and I started to regularly follow the activities of some of these autism-related groups (*Autismo Portugal, Mães Especiais, Autismo Pais em Rede, Pais do autismo, Vencer Autismo, Dar-Resposta, APPDA-Lisboa, Federação FPPDA*) as well as other groups related to the broader issue of disability and parent advocacy (*Pais em Rede – Associação, Media e Deficiência, Associação de Pais pela Inclusão*). In particular, I gave my preference to those showing a broader visibility not merely because of their virtual traffic or their number of subscribers, but above all because of the reputation and relevance of their role for parents.

Hence, the APPDA and the virtual groups I followed on Facebook represented the channels through which I met and engaged with my interlocutors in both informal conversations and in-depth interviews. Despite their own peculiar features of communication and encounter, both places allowed me to build a relationship with parents and to acknowledge the different ways in which they were dealing with autism in their private lives and within the public space. Parent-to-parent support groups - whether they have their headquarters in the physical territory of a specific town or in the cyberspace - represent places where parents share their experiences with other parents and search for information, encouragement and advice. Most of these groups have also advocacy purposes, as parents mobilise collectively and claim for health and therapies access, inclusive education as well as services and job opportunities for adult people with autism. In line with this, advocacy groups represent also the gateways through which parents manifest their civic engagement. At this regard, the broader aim of parents’ efforts on behalf of their children is to raise public awareness about autism spectrum disorder, to challenge social stigma related to infantile psychiatric conditions and intellectual disability and to improve social policies and legislation with regards to disability in Portugal.

In my ethnographic journey, I wanted to investigate parents’ advocacy practices and explore their ideas with respect to inclusion and citizenship, by focusing in particular on their use of the Internet and social media networks. Therefore, even though I started my exploratory fieldwork by contacting the APPDA, I later focused my research on online support and advocacy groups. In this regard, it is worth clarifying that virtual groups belong to the shared local (physical) context we inhabit in our everyday life. For these reasons my (n)ethnography is based in Portugal and especially in Lisbon, the city where I lived, encountered parents and participated

with them in meetings, conferences and other events. Advocacy practices of parents exist and occur in both the online and the offline world, showing the interlinked nature of both online and offline advocacy and also the fluidity between the offline and online ways of doing my ethnography. Despite I will sometimes mention the offline and the online as separate dimensions only for explanatory reasons, I will keep on writing my ethnographic account in a way that aims to be loyal to the interlinked nature of its sites of study in order to reproduce in some ways the “real” path of the fieldwork itself.

Some steps inside the fieldwork

In January 2013, when I contacted the director of the APPDA-Lisboa, I found out that I needed the agreement of Dr. Martín, the clinical psychologist of the structure, in order to contact some parents who usually attended the association. For this purpose, I brought with me a reduced version of my PhD project and a written statement in which I committed to maintaining the confidentiality of the information provided by my interlocutors as well as their anonymity. To tell the truth, the first meeting I had with the APPDA-Lisboa comes just with a dog. I almost arrived in front of a red gate of the association when a Cocker Spaniel, clearly irritated by my presence, started to run towards me barking. I remember that I was immediately tempted to run away and arrange another meeting with Dr. Martín but this (now funny) accident turned out to be something I eventually capitalized on my fieldwork notes. While I walked away from the Coker’s territory, two old ladies - that were chatting between their own house boundary wall - warned me (bad timing!) about the dog’s bad character. They also explained to me that I was at the back entrance of the residence where those *coitadinhos* (poor/unhappy/unfortunate people) lived. This expression, unfortunately, did not surprise me. The most part of the people that I later met by chance on my way to the APPDA-Lisboa or while I was waiting at the bus stop was used to refer to the APPDA by alluding to those who lived there: *os deficientes*.

Dr. Martín and I, we talked about the possibility that I could contact some parents through the association. After an informal conversation, he signed an agreement which allowed me to be introduced to the Direction coordinator, Dr. Ricardo, who would eventually help me to arrange some interviews with parents. He complained about the lack in Portugal of a solid plan able to implement strategies for mental health and social care services in community-based setting, as well as how State funding cuts affected the management of facilities like the APPDA and the provision of educational and therapeutical services. What I also remember about our

conversation it is me observing his sunken and sharp face and his dark green velvet dress, which recall me the farmer of the American Gothic painting by Grant Wood.

According to the agreement I made with Dr. Ricardo, since the APPDA functions as a diagnostic and therapeutic centre and I was not a user, nor a mother of a child with autism, nor a health professional, it would have been better if I did not move freely inside the building. I was suggested, instead, to wait in the entrance room or outside in the garden. Only on one occasion, as I asked for the bathroom, I glimpsed inside a room, which for its aesthetics and equipment design seemed to be a therapy room, and noticed a woman sitting in a table with a teen boy rocking back and forth. Despite the help of Dr. Ricardo, the negotiation to meet a parent took a long time. According to him, this happened because the most part of parents was quite tired of answering questionnaires given that the APPDA-Lisboa have been already used as a case study by several doctoral students coming from diverse areas such as clinical psychology, motor rehabilitation, nursing. I explained that I did not work with a questionnaire and that if some parents showed interest he could say that I was looking just for an informal conversation. The difficulty of Dr. Ricardo to “provide” me some parents was apparently due to a specific reason: they seemed to do not have enough time for me. Some parents attended the APPDA just for providing therapeutic services to their children, while those who regularly attended the association were quite aged parents that come just to visit their loved ones, adult people with autism that lived in the residencies of the association. The APPDA-Lisbon is, indeed, a mutual aid association providing diagnostic and care services, but it is also referred to as a long-life residential community for adults with autism, whose parents are elderly or already died.

I was finally introduced to Elisabete, a 72-year-old woman, mother of two women and of a 42-year-old man Jaime, diagnosed with severe autism and West syndrome²⁸, who lives regularly in one of APPDA residences from the age of 18. Elisabete belongs to the association from a long while and the medical and the administrative personnel trust her. While we were taking a walk in the garden, she indicated me the residential units where her son Jaime lived. It is now 4 years that Elisabete lost her husband. Things have changed since she can no longer count on

²⁸ The West-syndrome or Epileptic Infantile Spasms is an uncommon-to-rare epileptic disorder characterized by a symptomatic triad of muscle spasms, severe developmental regression and a pathognomonic (desynchronized) EEG pattern, called *hypsarhythmia*. The spasms may be isolated or in sequence and occurred up to a hundred times in a day.

her husband's physical help and affective support. First of all, Jaime did not join her at home during the weekends as before: "Now I'm alone and old and it's difficult for me to stay a long time with him" she tells me. Jaime's reintegration to home has never been an option for Elisabete as Jaime apparently perceives his mother's fear of staying alone with him:

"this freezes him, he starts to shake when he notices that I'm in the panic, do you understand? And then at home, he would not have the same quality of life that he has here...and for quality, I mean that in the morning when he gets up, there is always someone of the residence staff who cleans and dresses him up, who takes care of him and do everything, I can't do this, it's too difficult".

On a Friday of February, I had the chance to meet Elisabete again. She is used to visiting his son 3 days a week, on Monday, Tuesday, and Friday when a private rehabilitation therapist works with Jaime to help him to get out of the wheelchair and walk a bit. Indeed, he recently acquired the habit of clinging to people's arms or to oppose resistance when someone invited him to walk. I first met Jaime in the canteen. He was completely curled up in his wheelchair and a canteen assistant was spoon-feeding him yoghurt; he did not say a word, nor he seemed attentive to his mother's words. Elisabete eventually switched her attention to the canteen assistant - who has also a brother living as a resident - and I kept feeling the uncomfortable sensation that we were speaking about him as he were not there. Elisabete further confessed to me: "I always have this doubt...does he knows that I'm his mother? Or I'm just the person who cuddles him the most? I don't know if he just associates this to me, do you imagine what I feel?" When Jaime was diagnosed at two, the doctor told Elisabete that there would be no recovery hypothesis: "since then, I've lived with the idea that [autism] will be forever until the end of my life (...) her sisters are older than him, they work, they have families and children, since my husband died I dedicated myself to some hobbies...but I always try to come here, to give him all that I can and but you know when. I will die his sisters cannot leave their work and take him at home".

At the time of my visit, the APPDA attended around 60 persons between teens and adult autistic people and employed around 70 professionals, among which paediatricians, psychiatrists, psychologists, rehabilitation technicians, therapists, educators, teachers, plus the administrative staff and the personnel of the canteen. Because of a recent cut in public funding from the Ministry of Education, the APPDA could provide its Special Education program only to 5

children, while around 200 children from 3 to 14 years old who were attending public or special schools received subsidiary educational help and home support. After reaching the majority, some teenagers diagnosed with autism could attend the CAO - Occupational Activities Centre that disposes of different rooms (each available for groups of 6 people from the 9 am to 4 pm) for pre-professionalization workshops (textiles, ceramics, painting, cooking, gardening, floriculture, organic farming). Additionally, the Resources Centre for the Inclusion (CRI, *Centro de Recursos para a Inclusão*) aimed at supporting the integration of students with special educational needs (from now on SEN) in the regular education as well as at helping adults in their transition from school to working life. The APPDA counts also a music room, a gymnasium, a swimming pool, a library, a cafeteria, a laundry, a canteen with a dining hall, and a vast greenhouse²⁹. With respect to support services for adults with autism in need of long-term care, the APPDA offered 4 residential units each occupied by 7 adults, whose average age was 40 years old (the youngest was 30 years old and the oldest 62 years old). Most of these adults with autism have been also diagnosed with cognitive delay and other comorbid conditions (such as epilepsy, Syndrome of Rett, physical impairments, and gastrointestinal problems). The service provides 24/7 care in a homelike setting, including support for preparing and cooking meals, for household chores such as washing clothes, and for personal care such as getting dressed and undressed, and taking a shower. The residential care service is run in a joint venture with the State so that the rate of the monthly payment depends on the economic status of the user. As an example, as Elisabeth's husband was an army officer, she benefits from a special medical support (ADM - *Assistência na doença aos Militares*) of the Social Welfare Institute of the Armed Forces (IASFA - *Instituto de Ação Social das Forças Armadas*) and from ¼ of her husband pension. She pays €530 per month while his son's disability pension is used to partially pay the rehabilitation therapy. As an institution providing residential care, the APPDA operates according to a psychiatric semi-internment regimen. This means that Jaime, as any other residential user, is provided with a daily routine plan from 9 am to 5 pm.

At the APPDA, adults with autism have also the opportunity to leave the structure and do some activities in the neighbourhood, especially during fare trade, festive season or religious celebrations. For instance, several artistic products such as pottery and textiles realized during

²⁹ These represent some similarities with the "farm community" model of residential facilities for mental health patients whose first examples dated around the 1970s and 1980s and eventually spread over the years in many countries. According to this model, patients lived according to a daily activity plan and receive long-term care, psychological and pharmaceutical treatment and benefit from the support of a professional team.

the professional workshop at the CAO are sold to raise money at a craft fair - called Special Education Fair - which takes place every year in May in the Vasco de Gama garden in Belem. Several mutual-aid organizations undertake these alternative fundraising initiatives to cope with the reduction of public financial resources. Similarly, during Christmas or Easter, some residents can temporarily visit their family house. Jaime does not like to attend these events and that day of my visit he did not take part in the Carnival parade organized by the municipality of Lisbon. Indeed, as I arrived early at my second meeting with Elisabete, I saw some adult people dressed for the parade inside a minibus that would have taken them to the festival. I later took the chance to confess to Elisabeth my personal feeling of discomfort about that event: “Who chooses the costume? Are they aware of this? Do they know how to pretend to be a Carnival character?” While this infantilization occurred on several other occasions (I will address this topic in Chapter III), Elisabete told me of when a staff member put a funny hat on Jaime’s head against his will:

“even if he didn’t say anything, I realized that he hated that thing, he hated to see himself like that and that joke didn’t give him pleasure (...) me too, sometimes I still call him “my little boy” but he’s 42 years old, he’s a man now! There must be rules and I have to give rules also to other people, it’s a way to give him a good life, a good quality of life”

With regard to her experience as an advocate, Elisabeth admits that she never gets in contact with other parents: “we never approached, because all of this [her son’s diagnosis] happened 40 years ago. Now parents have the Internet, they seek doctors’ support and meet with other parents and help each other...but 40 years ago there was nothing similar”. Her answer is in line with her own personal experience. For instance, she would not change anything with regards to her son’s well-being: “at his age” she said, “I just want to give him a comfort place to live, you know, inclusion is a nice thing but I doubt about the possibility that these guys can improve...maybe when they are still children but even in this case the teachers at school are not prepared and you have still classrooms with 20 or more children!” I was not surprised by Elisabete’s explanation. Like her, the other few parents that I encountered inside the APPDA have their relatives living as semi-institutionalized patients. These people were diagnosed as “autistic” during the early 1970s-1980s, they benefited only few therapies and the most part of them was institutionalized after compulsory school. For these reasons, the most part of these parents hopes to ensure their relatives long-term care and the best quality of life possible. The social inclusion of these people is restricted to the participation in some “events” occurring

during religious and civil festivities or inside specific places such as craft fairs or Carnival parade. Moreover, due to co-morbid condition and to severe cognitive and intellectual disability, these adult people with autism are subjected to parental and institutional guardianship and deprived of any opportunity for achieving inclusive citizenship (Chapter VI).

Taking these aspects in consideration, it is important for me to stress out a relevant turning point that drove my fieldwork from then on. Elisabeth's case shows how there is a very clear difference in advocacy practices between older and younger parents. This difference lies in the topics and issues they are advocating for as well as in the tools they use to claim on behalf of their children. Actually, as I was particularly interested in the use of social media networks and Internet as instruments for and places where parents advocate for their children and young adults with autism, during the following months I focused my attention on younger parents. I still had the chance to encounter some of them at the APPDA, but later I used to keep growing my contacts using the so-called "snowball method", with initial interlocutors suggesting other potential parents through the intermediary of their networks of acquaintances. Although this method elicited a rather diverse population, the most part of the parents I met were women.

What does it mean to be an advocate?

During another day of fieldwork at the APPDA - which I no longer visited as a fieldwork site after May 2013 - I was sitting in the entrance hall waiting for some parents whose children attended the association as a therapy centre. At some point, a speech therapist - that I was used to meeting there - appeared with a woman and her male toddler. The therapist greeted me and continued to talk with the woman, putting down her handbag and her 24-hour briefcase on one of the chairs arranged in a semicircle shape. A few minutes later, a boy in his thirties took both of them and carried them away without giving me the time to stop him or to say something. I suddenly get up, worried, while the speech therapist reassured me that the boy was used to bring her bags in her car as a kind of personal task, as a responsibility that he impeccably accomplished every day. I smiled, a bit embarrassed for having thought that the boy was doing something wrong. This fortuitous event gave me the chance to speak about my on-going research as the speech therapist asked me how the fieldwork was going on, and she eventually introduced me to the woman by giving her a concise yet accurate description of my research.

Lucia is a 32-year-old mother of Paolo, a 4 years-old child diagnosed with autism, who attends speech therapy for some language troubles, especially with articulation (like saying certain

sounds or words correctly) and fluidity (he repeats certain sounds and has trouble saying a complete word or sentences). Lucia is afraid she will not have much time for me, “I’m always running from side to side of the city” she said. Throughout my fieldwork, the phrases “I have no time” and “I’m leading a very busy live” represent the most common answers and reasons parents (especially mothers) advance to justify the impossibility to meet me, which often results in my own frustration. Lucia and I, we decide to keep in touch and to meet after Easter 2013 without succeeding to schedule a coffee. We later exchanged some emails during the summer till we managed to meet in February 2014 when I eventually invited her to visit a photo exhibition about autism³⁰. In order to reach the site of the exhibition, we planned to take the bus together at the Rato station. Lucia is in a good mood, we chat about various things while Paulo attracts the attention of people around him by flapping his hands. As if we were accomplices of an implicit alliance, we both replied with a smile at those curious glances. Heartened by this complicity, I asked her why Paulo emits kind of beep-like sounds at an almost regular distance, “it’s the way he figured out that we will take the bus” - she answered. When we finally entered the bus and validated our tickets, Paulo had the beep he was so much waiting for! Lucia and I kept talking informally about her experience, while Paulo looked out at the city through the window. Later, I will write down in my field notebook about Paulo’s restlessness, about his pupils moving frantically as if they wanted to grasp everything around him.

Since the APPDA was the shooting location of the photo project, I easily recognised some of the people - mainly male adults with autism - that I have already crossed inside the association. The photos reproduce different landscapes and emotional situations: a boy crouched on a sofa in a foetal position or another caught while hiding part of his face, an adult man leaning his head on the desk in a position suggesting boredom or despair, mature hands playing with a wooden peg puzzle made of colourful shape pieces identified by farm animals illustrations, other men with smiling faces or with unfocused gaze both visually referring to mental retardation, corners of the APPDA photographed as if they were still life paintings. Moreover, the use of black-white printing had a large impact on the images as it shadowed them with a mixed feeling of anxiety, solitude and sadness. Lucia is visibly annoyed “autism is not just silence and loneliness”! Her judgment about the supposed project’s purposes is quite harsh, especially because she personally believes in the social role and political impact that artists and public figures could have in undermining the media discourse about autism as a tragedy: “the

³⁰ *Em si mesmo. Uma viagem pelo autismo*, a photo exhibition of the authorship of Luís Barata (Centro Cultural Casapiano – 16th January to 28th February 2014) - <http://luisobarata.wixsite.com/ensimesmo>.

worst is that media spread this dreadful vision of autism by leveraging the feeling of sorrow and pity for disabled people's condition!" she said, "and this photo exhibition takes exactly advantage of this!" According to her, since artistic projects and cultural events can achieve public resonance and reach popular opinion they should actively support parents in spreading a different vision on autism in order to educate people and prove them that living with autism is not a tragedy but a different way of experiencing the body and social relationships.

My encounter with Lucia was particularly responsive to my purpose of investigating parents' discourses and practices of advocacy. Indeed, when I succeeded to informally meet parents or to participate with them in meeting and events, I felt that we were both at ease talking and sharing more intimate and personal ideas about autism advocacy. This informality also allowed me to be part of parents' everyday life and see what advocacy means in practice. As an example, I once commented on the Facebook page *Autismo Portugal* a post of a mother complaining because her son has been rejected from a school trip because there was not any support teacher available. I wondered if she could address some institutions in order to file a complaint and Irene - a mother of an 8-year-old boy Osvaldo - informed us about a forthcoming training course on the topic³¹ sponsored by the INR - *Instituto Nacional de Reabilitação* (National Institute of Rehabilitation). Since I showed my interest in joining the initiative, Irene sent me a private message with the course's inscription procedures and agreed to go there together. The training course was about the Convention on the Rights of Persons with Disabilities, the international human rights treaty adopted by the United Nations General Assembly on 13 December 2006 and approved by Portugal in 2009 and was focused on the "Article 5 - Equality and non-discrimination". Seven people - among which parents, educators and students - attended the course. The INR trainers presented us the legislative measures envisaged by the Portuguese Law of non-discrimination (*Lei de não discriminação*, n. ° 46/2006), which prohibits and punishes any act of discrimination against people based on disability and aggravated health risk. We eventually learned how to file a discrimination complaint and send it to the institutions accredited for this purpose. Irene was particularly interested in the course's topic because the school director of his son's public school suggested her to enrol Osvaldo in a special school from the next school year, as he may no longer receive a special teacher support.

³¹ Cf. "Convenção sobre os Direitos das Pessoas com Deficiência - Art. 5º Igualdade e não discriminação: medidas e procedimentos", 3rd July 2014; www.inr.pt/content/1/2538/acoes-realizadas-em

Social media networks and in particular Facebook-based groups, as shown by the above example, represented online interfaces through which mothers and fathers share their stories, get involved in a conversation, establish a relationship with other parents and expand their network of contacts. Online groups were crucial also for my fieldwork insofar they keep me easily up with different events, lectures or seminars promoted by autism associations or other institutions. During these occurrences, indeed, I had the chance to encounter parents in a face-to-face context for the first time or to meet them again and strengthen our relationship. For instance, on the World Autism Awareness Day (WAAD) - which is celebrated worldwide on the 2nd of April - the APPDA organized every year a symposium according to the guidelines of the international association Autism-Europe. Under the auspices of 2015 theme “STOP discrimination”, Autism-Europe called for decision-makers and political leaders across Europe to take action to prevent discrimination and promote inclusion of people with autism across the lifespan. The online network *Autismo Pais em Rede* used its Facebook page to encourage parents to participate at the event in order to gain more visibility in front of political representatives and to testify the presence of more informal communities of parents within an event mainly planned by autism associations formally recognized by the State, such as the APPDA. During the sessions’ breaks, some parents formed informal circles, which revealed to be precious moments of debate and sharing. I eventually joined a group who recognized the importance of the event in gathering parents, political figures and diverse scholars working on autism and disability rights but doubted about its real achievements. Rute, a young woman who fiercely said to do her fight on behalf of her son in “her own way”, regretted having participated in the event as it made her feel more frustrated:

“again and again the world is painted in blue (the colour associated with autism awareness day)³²
but the path to equality for citizens with autism is still in its early stages (...) and this has nothing

³² The light blue is the colour of the logo of the most well-known and controversial autism-related organisation called Autism Speaks. This organization started the “Light It Up Blue” campaign - that was eventually at the basis of the association of the blue colour with autism - with the aim of raising autism awareness by lighting up buildings, icons and landmarks in cities all over the world on April 2nd (<https://www.autismspeaks.org/liub>). Autism Speaks is criticized for not being represented by any person diagnosed with autism and for behaving as a profit organisation (here two blog entries that summarise other controversial critiques www.autistichoya.com/2013/11/coopting-the-movement.html and www.theodysseyonline.com/7-reasons-not-support-autism-speaks). While some critics argue that the light blue is just another powerful marketing campaign, on its website Autism Speaks explains that “the colour blue represents the boys diagnosed with autism” since ASDs are more common among boys than girls (www.autismspeaks.org/blog/2012/04/02/shine-light-autism-roscolor-color-filters). Baron Cohen (2002, 2010) addressed the gender-based difference in autism diagnosis and proposed the “extreme male brain hypothesis” to explain the male-female gap in autism diagnosis. The author thinks sex differences by referring to the dimensions of “empathising” (female) and “systemising” (male) and defines autism as an extreme of the male systemising dimension. This theory has been powerful in shaping public

to do with having better diagnostic tools and new laws. For me, for moms like me, things do not change like that. Today [April 2nd] I have nothing to celebrate. It is another media catwalk”.

Rute’s bitter irony contributes in a very powerful way to assert her ideas. In her opinion, celebratory events, such as the WAAD, underline the fact that people with autism and their families still struggle for treatments, educative support and social inclusion, remembering us as a society that disabled people have not yet achieve a quality of life worthy to be called as such.

During the same event, I had the chance to meet Ivo, father of a ten-years-old boy with autism, Alex and of an older son diagnosed with dyslexia and attention deficit. As a disability policies’ expert enrolled in a PhD in Public Policy, he participated in several national and international studies and projects in the areas of disability. In that occasion (2015 WAAD) he has been invited to present his research on the Portuguese employment market for people with disability, made in collaboration with the Portuguese Federation of Autism (FPDA). He introduced to the audience two recent online platforms³³ that, by articulating companies, local associations and other organizations, aimed at facilitating the inclusion of people with autism in the labour market: “To hire people with autism is a human rights issue and a good business for employers!” he concluded his speech. At the time of our encounter, Ivo worked as a sociologist at the Strategic and Planning Cabinet of the Employment and Social Security department of Ministry of Solidarity, Employment and Social Security and a few months later he will be promoted Head of the Cabinet at the Secretary of State for the Inclusion of Persons with Disabilities. Some weeks later, I eventually met him at his workplace on the 4th floor of the big blue skyscraper building of the Ministry. He was pleased and proud to be interviewed - “you run on the right person!” he said to me - and he plentifully spoke about his singular experience as a father and academic that has also a prominent role at the FPDA and at the Ministry of Solidarity.

perception of the condition as a male disorder. Some critics argue that, because of this statistical gap, women’s autism is often overlooked or diagnosed late (<http://autisminpink.net> and <http://www.autism.org.uk/about/what-is/gender.aspx>). The other symbol of autism is a puzzle ribbon that was adopted in 1999 as the universal sign of autism awareness. Although this image is a trademark of the Autism Society, the organisation has granted use to other non-profit organisations in order to demonstrate unity instead of any individually held interests or promotion of a single organisation (<http://www.autism-society.org/about-the-autism-society/history/autism-awareness-ribbon/>). In the ribbon symbol, the colours of autism are red, yellow and blue, representing the diversity of people and families living with autism, and the ribbon’s pattern is a multicolour puzzle piece, whose pieces reflect autism’s complexity.

³³ See <http://plataformainclusao.fpda.pt> and <http://autismoetrabalho.fpda.pt>.

Ivo started to get involved with disability policies in the 1990s, a period - he said - when social inclusion for disabled people was not even mentioned as a social issue. When in 2006 at the age of 2, his son Alex was diagnosed with autism, his own job became an instrument of advocacy and eventually joined the FPDA as a member of the Executive Council. In this regard, despite he strongly believes in the importance of online and informal advocacy groups - as they result in emotional bonds, friendship and mutual learning between parents - he considers the Federation the only “real interlocutor” with the State:

“I’m a friend of all of them [parents who participate in online advocacy groups], but if we want to have a voice, we have to lobby with it [FPDA]! Only through strong institutions, we can claim for change, we can only do this within an association that has access to power, that has a voice and is respected and we as parents we should converge in this vision. We are all fighting for inclusive school, therapies’ access, social inclusion and to make our children participate in society, but we need an institutional set-up”.

Not all the parents attending the conference would agree with Ivo. They often criticized the FPDA for not listening to parents’ concerns and not accept criticism, remaining loyal instead to its institutional power ties. At the end of the conference, when some parents in the audience asked for a debate session, the Federation committee let know that this was not scheduled.

Laura, a young mother that I first contacted online through a mutual friend, preferred to not get formally involved with any support and advocacy group for several reasons. Actually, she left the local support group that she was initially attending because she felt that “the focus was always on problems, [and that] there were those parents in crisis that acted like we were in Alcoholics Anonymous ‘my name is x and my son has autism’”. She did not feel at ease to share her experience and she thought it was “detrimental” to belong to the group because she felt unnecessarily overwhelmed by other parents’ problems. As she failed to identify with their concerns, she missed to find a common ground with other parents attending the group. As she said:

“the autism of Oscar [her 4-years-old son] has compromised his communication and fine motor skills, but he is more intelligent than many of us! He is an extremely caring child, his memory ability is above the average you know...since the age of 2 [when he was diagnosed] he counts and recognises numbers up to 5 digits, he knows the whole alphabet, he is really smarter than an average child”.

Since Oscar's behaviours and peculiarities correspond to a so-called "mild form of autism", he does qualify for speech therapy just once a week. Laura, however, demands that Oscar is provided with some more therapies from the State "like other autistic children". Moreover, as she said, "as an activist, I talk openly about my son's autism with others; also, in the street. I read a lot about autism and I follow different online parental groups to gain different opinions and more control on the information I'm seeking... but I prefer to do all of this by my way".

These ethnographic vignettes revealed how parents use a variety of advocacy styles and have different goals. Despite throughout this dissertation I will employ the expressions "activist parents" or "autism advocates" to generally refer to parents who advocate on behalf of their children, parents can be not reduced to a homogenous group. Some of them advocate in a more independent and private way, others identify themselves as part of a specific advocacy group while others prefer to occasionally or temporary belong to one or more groups at the same time. They choose different instruments to put in practices their claims on behalf of their children, each parent demands' may change over the time when new goals are set up and old goals are attained, like the actions they performed as advocates. This variability depends also on a parent's age, on each child's needs and characteristics, and on the intimate experiences that parents do by living and caring for their child.

Relations and interactions

Since my research's interest is to explore parents' use of the Internet and social media networks as an advocacy tool, in what follows I will introduce how I get access to *Os Amantes de Saturno*, the main Portuguese online support and advocacy group for parents of children with autism. This group eventually became the key virtual site of my ethnography. While interacting online with my interlocutors, I have also maintained and made new acquiescence through snowball method and common friends. I will discuss, then, some of the relevant issues and topics that emerged from both online and offline interactions, as well as from in-depth interviews and informal conversations. This section's aim is to acknowledge parents' everyday experiences in living, caring and relating with their autistic relatives by exploring the main topics they used to discuss within the virtual community.

Os Amantes de Saturno

While at the beginning my ethnography on parent-led autism advocacy groups in Portugal spanned several groups, from April 2015 to February 2016 (with exception of the months of

July and August) I eventually restricted my research by localising the fieldwork on *Os Amantes de Saturno*³⁴. My encounter with Ivo was particularly relevant for this purpose as it prefigured my access to the group. *Os Amantes de Saturno* is a closed Facebook-based group created in November 2010 by a mother of a child with autism. In a closed group, the membership process requires that the administrator itself approves each membership request in order to assure that everyone in the group is a trusted individual. My request of membership needed the approval of Diogo, the administrator of the group and father of a young boy with autism, who is also appointed to supervise the online content and to moderate online interactions among members. Ivo offered to favour my application for admission to the group. While at the beginning, *Os Amantes de Saturno* was directed only to parents of people diagnosed with autism, Diogo enlarged the membership also to health professionals, (such as doctors, therapists, and psychologists), special education teachers, educators, researchers like me, and “friends of the cause”. The most part of the active members, however, are parents. Every member is allowed to post or comment, to share information, video and links and it is also possible to upload legislative documents and autism practical guides for parents, which provide a useful archive.

Once my membership was approved, Diogo greeted me with a sample welcome message in which he informed me that the group aims at “sharing adventures and misadventures related to autism, good days and bad days, we talk respectfully, and we help each other with our experiences”. In the welcome message usually sent to new members who are also parents he adds the phrase “if you need to vent, we’re here!”. The group, indeed, give parents the opportunity to speak about their everyday experiences in a “safe space” where people could really understand each other. Some parents greeted my admission and I soon introduced myself and explained my research and why I wanted to be part of the group. Throughout the lifespan of the fieldwork, I have always clarified and explained my role as a researcher every time I thought was necessary, using my real name, my actual position as a PhD candidate and the aims and intentions of my project. Despite the group counted with more than 800 members, only almost 30 “active members” visited more frequently the platform and posted, commented and engaged in conversations with other members. The approach of digital ethnography allowed me to observe and participate in this online community, to map the most urgent autism-related

³⁴ Literally translated in Saturn Lovers, the group’s name refers to a controversial astrological theory according to which people with autism or Asperger syndrome may be affected by the influence of Saturn. The planet, that represents the individual or egoistic liberty and rules order and structure, apparently leads these people to appreciate their own company, to have few friends and difficulty in finding a partner, as well as to be very reserved and shy.

claims and issues shared online, to discuss them with parents themselves, and to be informed about the different types of events (conferences, meetings, workshops, petitions, marches) organised by them or by other autism associations. As long as my presence became more familiar, I have built closer and trusted relationships with some parents who I eventually met also in face-to-face contexts. Indeed, as it occurs in snowball method, I imagined *Os Amantes de Saturno* as another place where I could meet parents, as well as to construct my personal network of acquaintances. In broader terms, within this online support and advocacy group parents encounter with other parents and act as active gatekeepers by selecting autism-related information - such as events, scientific articles, studies and news - to share with other members. Parents use also the platform to implement their socialisation by promoting recreational activities (like picnics, screenings at the cinema or holidays) or by sharing public events (such as a photo exhibition, conferences, workshops or official meeting dedicated to ASDs) such as those I had the chance to attend and where I eventually met some parents. Being part of the *Os Amantes de Saturno* implicates a strong sense of belonging. Beyond the possibility to share experience and to access relevant information, parents do not need to physically dislocate as would happen if they were attending offline mutual support associations. For this reason, many parents emphasise the high level of “accessibility” of the virtual group, which has in this sense a more active role in circumventing geographical boundaries. This turned to be a relevant element for those parents who do not have local support groups in their areas of residence or whose meetings’ schedules were not compatible with their work and family commitment.

The majority of these parents argued that their life changed once their child was diagnosed with autism. Their experiences were very different from those lived by “typical” families, namely families with a typically developing child. They feel there is no way they can ask for or expect other people to understand their experiences. Things usually become easier once they receive some social support but even then, the support available and the space for sharing their feelings may be very limited. This is why parents described the importance of being able to attend support and advocacy groups insofar as they offered a place to share experiences and information, to ask for advice and encouragement. Likewise, many parents of newly diagnosed children highlighted the importance of talking to “old-timer” parents who thanks to their past experiences could share their expertise and give precious advice and reassurances to “newcomer” parents. Older parents have a central role in supporting and encouraging younger parents, in strengthening online affective bonds between the support group’s members and in celebrating their newfound friendship and bond as parents of children with autism.

Furthermore, in a parent-led group - as once Irene said - “you don’t have to explain everything from the beginning as happens with parents of the so-called normal children because they already know what is going on, and thus they won’t judge you”. Irene’s words underline how mutual support is central also in helping parents to heal isolation and social stigma. Parents finally reported how they mutually learn from each other, easing their search for information and achieving precious knowledge about their children. Some of them had developed a more public “active role” by raising awareness about disability rights and campaigning for all people discriminated because of a disability, turning their personal advocacy on behalf of their children with autism into a broader disability activism (Ryan and Runswick-Cole 2009).

Parents’ search for and reactions to their child’s diagnosis of autism, the process of learning from and adaptation to their child’s needs, traits and behavioural characteristics, the social stigma they often lived in public space represent some of the experiences that influenced the most parents’ life and their personhood, their ways of parenting and their involvement in autism advocacy. In the following paragraphs, I will explore what it means to live and care for a child with autism by reporting the experiences that parents shared in *Os Amantes de Saturno* and described the main topics they discussed in this process of learning and adaptation. This overview aims at illustrating parents’ daily compromises and struggles and at acknowledging their deep involvement in their children’s lives and the profound understanding of their necessities and characteristics. Despite the difficulties, parents make efforts to reconfigure their lives in meaningful ways. Their *unique* understanding of autism represents a key factor in order to be publicly recognized as those entitled to act in defence of their children.

Unmasking autism

Several ethnographies and articles have shown how in parents’ narratives about autism the diagnosis is usually reported as the first life-changing event (Benson and Karlof 2009; Grinker 2007; Lickenbrock, Ekas, and Whitman 2011; Osborne and Reed 2010; Silverman 2012). Looking for and finally getting a diagnosis is indeed not merely a biomedical process that identifies the nature of a disease, but it is also a demanding and challenging emotional experience. According to its etymology - διάγνωσις from the Greek verb διαγιγνώσκειν, meaning “to discern”, “to distinguish” - a diagnosis is a noun that recognizes a disorder or a disease by distinguishing its traits and symptoms.

Since there are no reliable biomarkers that prove autism's existence, an autism diagnosis is based on a range of behavioural symptoms, among which social difficulties, fixated interests, obsessive or repetitive actions and unusually intense or dulled reactions to sensory stimulation. While great advances have already been made in trying to figure out its aetiology, there is no known single cause for autism, but it is generally accepted that it is caused by a combination of genetic, environmental and neurobiological alterations and differences in neuro-processing. Also, the definition itself of autism as a "spectrum" is controversial as it suggests the idea that it manifests in a straight line starting from less to severe traits. In this respect, philosopher Ian Hacking (2010) proposes to define autism as a manifold:

"It is now common, perhaps even standard practice, to write about the autistic spectrum, and of autism spectrum disorders, standardised by the initialism ASDs. I don't. Since ordinary spectra are linear, this jargon misleadingly suggests a single dimension from severe to high functioning. Spectra come from physics. Think of Newton's red-orange-yellow-blue-indigo-violet produced by a prism, which we now know to be a continuum of increasing wavelengths. Autism is not like that. Metaphors tend to be dangerous. I think 'manifold' is pretty safe" (idem:635).

The standard diagnosis of ASDs *per se* risks to hide the particularities of each person. Between two individuals diagnosed with autism, indeed, there are variable and profound differences. Also, the distinction between low, middle and high functioning (Asperger) autism implies the idea that differences displayed by people diagnosed with autism could be classified according to a degree of social functionality. Actually, no one is likely to show all the symptoms defined as typical of each supposed type of autism and functionality is a controversial criterion, which may involve different features from high IQ, high performative academic abilities and verbal communication to the ability of independent living and self-caring. In this sense, "functioning labels" are basically another way of saying whether or not a person with autism can pass for a neurotypical (normal) person. In my fieldwork, parents described their children in very different ways and I have personally met persons with autism that, although having some traits in "common", show their own peculiarities, strengths and challenges. From these observations, I can argue that autism actually includes and refers to a multiplicity of behaviours and characteristics that each person shows according to her distinctive traits. This extreme variability of people described as "autistic" or "having autism" is often difficult to translate into writing. This is why, rather than localise children in a point of the spectrum - as it was possible for a person to "fall" in a very precise place along the autistic spectrum - I will try to describe

them according to parent's experiences or (when possible) to my personal experience. I think this is the only way to show how, actually, people with autism show a continuum and time-changing set of different traits.

When relating their path into their child's autism, parents usually report how some "first signs" aroused their concern such as delay in language, lack of eye contact, repetitive and stereotyped behaviours, echolalia and some difficulties in interaction. These memories marked the moment in which parents "found out" that something was not going in the right way. The most part of the parents considers clinical diagnosis as a poignant event as it proved how their concerns were real, and also because it compelled them to accept their children's condition and to commit their future with them. A diagnosis of autism informs parents about the traits and symptoms usually associated with the disorder, gives them a name to organize and identify their child's "difference", and drives them to learn how to "deal" and raise a child with special needs and how to negotiate with the tangled bureaucracy of public health services, social supports, and educational programs. Their reactions to their child's diagnosis may significantly differ, yet it is quite generally remembered as a turning point in life that despite feelings of discouragement and despair led them to positively rethink about life and future.

In this respect, Hacking (2006) describes autism diagnosis as a process through which biomedical and psychiatric discourses "make up people". In particular, autism represents for the author an interactive kind, meaning that as a psychiatric label it interacts with people, ideas and actions and at the same time it can be transformed by these interactions. Autism, in other words, is produced through a "looping effect", a mechanism through which "new knowledge about [a psychiatric category] becomes known to people classified and changes the way these individuals behave, and loops back to force changes in the classification and knowledge about them" (Hacking 1999:105). Although it may seem problematic to associate autism with the idea of an interactive kind, as people with autism are generally portrayed as having severe problems of communication and self-consciousness, the author argues how by interaction we should mean not only "the self-conscious reaction of a single individual to how she is classified" but also "the consequences of being so classified for the whole class of individuals and other people with whom [children with autism] are intimately connected" (idem: 115). In order to show how people and institutions interact with the label of autism, de Wolfe (2014) reports how when "the label 'autism' interacts with a new piece of health insurance legislation that details the symptoms necessary to receive coverage, those symptoms may be recorded by doctors more

often to help families receive coverage and, in turn, those symptoms may soon seem more characteristic of the label than others” (idem:12).

Following these considerations about autism as an interactive kind, I will report how parents’ ideas about their child’s autism vary according to their own personal background and knowledge. For instance, for Pedro - an English teacher and a single parent of a 12-year-old boy - the word autism “means nothing”, it is just the result and the official name of a technique [the diagnostic procedure] that gathers his son’s stereotyped and repetitive behaviours and his non-verbal communication into a label. Yet, the diagnosis and the proof of the psychiatric category represented for him a “necessary” step in order to face his own existential and emotional crisis and helped him to find some relief and support:

“Yes, you know parents are completely confused, I was full of emotions and at the same time, my mind was empty. It is bad, very bad to hear those words and the doctors you know...maybe on the same day they might have said the same things to other parents. For them it is like ordinary administration...but at the end, I finally manage to know what was not going well in Francisco [his son]. It was a terrible blow, but I felt relieved, you know if something has to happen let it happen! This is important for you to go ahead”.

For Helena, the diagnosis of his son Vasco (now a 15 years-old teen) has been a relief as it confirmed what she already knew: “I knew that he had a mild form of autism because my husband who is now 51...he is the same! Even though he has never been diagnosed!” Autism severity is thought to be a significant factor affecting parental reactions to diagnosis. Parents of children showing more severe symptoms, for example, struggle more to accept the diagnosis and adapt to their child’s needs (Poslawsky et al. 2014). This assumption does not necessarily imply its contrary. Indeed, although a diagnosis of “mild autism” or Asperger may suggest at first a more positive reaction, this is not always the case. Luisa, for example, is still struggling with the idea that his 6-year-old boy Igor has Asperger and her family - she said - still does not accept the diagnosis.

Similarly, several parents describe their feelings of despair, sadness, and anger after their child is diagnosed with autism by referring to the so-called “mourning process”, a term describing the time elapsed from a beloved’s death till its acceptance. The allusion to mourning suggests parents’ emotional response to sorrow and helps them to alleviate the grief for the loss of the

child - a “normal” child - they were expecting to rise. In this respect, some scholars have focused on mothers’ reactions to ASDs diagnosis, underlining their emotional struggle to cope with the loss of expectations for a typically developing child, as well as with uncertainties regarding the child and family’s future (Dale, Jahoda, and Knott 2006; Wachtel and Carter 2008). At the same time, in my experience, the resigned sorrow for the expected child is not lived and described as inevitably devastating and frightening. As an example, Olivia, a single parent and an educator finally “faced the reality and went to the fight” when his son Fabio (who is now 20 years old) was diagnosed with autism. As she emphasises, “I always had a feeling that if I had a child it would be special!” Zelia, a part-time librarian and a single mother of a 13-year-old boy named Leandro, argues how after the diagnosis she gradually become “disenchanted” with her dream of having “the cute and beautiful baby that all mothers want” and that after “crying this broken future and coping with this grief” she eventually started to fight for her “real child!”. On the contrary, when the doctor communicated to Barbara that her son Eduardo (now with 14 years-old) had severe autism associated with cognitive deficit, she felt like someone “swept me off my feet”. As she once wrote me in a private message: “only after much pain, disbelief and revolt I’m now starting to accept it [her son’s autism] and I’m still working on it day after day”.

These brief ethnographic sketches suggest that despite their different initial reactions parents always tried to not give up to sadness and despair when a diagnosis of autism is pronounced or “validated” by doctors. The will to struggle for their children’s needs took the place of sorrow and fear and motivated parents to positively transform their expectations. Almost all the parents I encountered recall how they felt the need to re-configure their desires, hopes and future expectations about their child, as well as their own personal, conjugal and familiar life. This is why the mourning process is generally interpreted by parents as a “phase” during which they finally embrace their “real child” instead of the “imaginary child” and settle on the idea of living their life according to the needs of their children. These adaptations are so significant and profound that sometimes fathers and mothers speak about a life “before and after autism”. As some scholars argued (Ludlow, Skelly, and Rohleder 2012; Ooi et al. 2016), mothers and fathers of children with autism face lifelong adaptations to their child’s needs, by adjusting their life to the long-period challenges of living and relating with their child over the time. These considerations underline parents’ continuous negotiation and re-signification of parenthood and parenting practices as their children grow up. In this regard, since the most part of mothers I encountered usually present themselves as the main figures of emotional support for the family

and ultimately as the main caregiver of a child with autism, I will discuss in Chapter V the gendered politics of care and parenthood, and the use of affectivity in advocacy practices.

Sharing and learning how to live with a child with autism

After their child received a diagnosis, parents usually come in contact for the first time with other communities of parents, especially through mutual support and advocacy groups that are thought to increase family's coping strategies over time (Gray 2006; Hall 2012; Hall and Graff 2011). Thanks to a new network of support, parents learn how to face the difficulties about living and relating with an autistic child, how to become caregivers and educators of a child with special needs, as well as how to handle and manage the procedures that will allow their children to access services, such as medical care and educational supports. Parents learn from other parents' experiences, they ask for and receive guidance, they benefit from each other encouragement and they gradually gain confidence in their new (and still in progress) parenting learning process. Despite the hardships, parents describe the significant and positive experiences that resulted from raising a child with autism (Altiere and von Kluge 2009). Support and advocacy networks help them to find acceptance and to mobilise resources to help their child. These material and emotional benefits are thought to be particularly crucial for mothers who, because of their main caregiving role, are supposed to cope in a more positive way their mothering experiences in raising a child with autism (Markoulakis, Fletcher, and Bryden 2012). Speaking about support programs and services, parents complain that they are usually waiting years to really get therapies and interventions, as well as to get psychological and financial support. Often parents judged that the competence of health professionals is not sufficient nor in line with their own experiences of living with a child with autism. Barbara, for example, accused the child psychiatrist to have dismissed her worries in a coarse manner and with heartless remarks such "Oh mother, don't worry! It will be worse when he will be older!". Negative experiences led parents to no longer entrust doctors who are accused of "destroying dreams", of "waiting for parents to give up" or of "hurting them with their indifferent words". This dramatic situation is complicated by the fact that local health institutions do not dispose sometimes of funds or sufficient specialised personnel to cover the number of requests. This is why most parents' first reaction is to learn "all you can about autism" in order to acquire an expertise in both medical and non-medical knowledge (psychiatry, psychology, therapies, law, social education).

Scholars explored how through the use digital media (such as social networks sites, forums and online communities) people with disability are rewriting an alternative account of their identity (Kirmayer et al. 2013) and families' patients "are turning to each other to supplement doctor's advice, devise treatment strategies, discuss side-effects medications, seek emotional support and organizing advocacy campaigns" (Coleman 2010:495-96). In my analysis, I have identified some of parents' purposes when using online support groups, such as sharing doubts and concerns, asking for advice with regards to health professionals, alternative treatments, diets, as well as finding encouragement. For instance, in the *Os Amantes de Saturno* parents very frequently asked for therapy's advice. More "experienced" parents, namely parents who have already experience in raising an autistic child, are usually the first resources and interlocutors of those parents who are "new" in the path of autism. Drawing from their own understanding and practice, they transmit their know-how and encourage other parents to rely on their own abilities in order to deal with autism. As I have already emphasised, autistic children show a large variety of symptoms and levels of impairments. As a result, their daily life is affected by difficulties ranging from minor to overwhelming limitations that may require institutional care. For instance, some children have a very high IQ, others have deep linguistic and cognitive deficits, some others can easily communicate, and others are described as caught up in their own universe. Therefore, parents deal with and adapt to different disability issues. Pedro and Zelia, for instance, have evaluated over the time different treatment plan for their children following their children's specific needs. In general, parents are constantly seeking to expand their treatment choices and similarly most child psychiatrists and therapists follow a combination of diverse methodologies and approaches, targeting their intervention all along the different stages of a child's growth. Similarly, parents inquire other parents about medical professionals, such as therapists or neuro-psychiatrists, who demonstrated to be particularly "sensitive" or specifically trained in ASDs, as well as ask or give advises about therapeutic centres specialized in alternative therapies such as animal-assisted therapy and sport-related therapies (adapted aquatic activities or psychomotricity). These, as well as other more classic therapeutic treatments, have usually a significant cost and the State do not cover it. The ABA therapy, for example, generally employs one-on-one tutoring for a maximum of 40 hours each week, which results in really expensive bills. Even if some parents disapprove ABA as a technique that denies children the right to be who they are (cf. Chapter I), others recognize it as boosting communication and social skills.

In the virtual group, parents also frequently debated about the use of psychiatric drugs. Pharmacologic treatment for autism is supposed to reduce certain behavioural but its use represents a very contentious issue. In particular, parents discussed about the use of methylphenidate, a stimulant of the central nervous system sold under the trade name of Ritalin, in order to treat their children's hyperactivity, as well as of topiramate (an anti-epilepsy drug) and of aripiprazole and risperidone, two antipsychotic medications, also prescribed for the psychiatric treatment of schizophrenia and bipolar disorder. These antipsychotic drugs have been found to reduce some autism's features such as irritability (Kirino 2014), aggression toward others, self-injury, temper tantrums, and rapid mood changes (McPheeters et al. 2011; Posey et al. 2008), minimising also repetitive and (so-called) maladaptive behaviours (Benvenuto et al. 2013; Sharma and Shaw 2012). As a result, those drugs are supposed to facilitate social inclusion by helping the autistic child to reach a "functional level (Doyle and McDougle 2012; Weeden, Ehrhardt, and Poling 2010). On one hand, some parents are favourable to psychiatric drugs' prescription insofar as they often improve their children's sociability by reducing tantrums, aggressive outbursts and self-injurious behaviours. On the other hand, they also complain how child psychiatrists show no hesitancy in prescribing these drugs "as they were cough syrup", nor do they seem aware of the side effects of long-term consumption. Antipsychotics, in particular, are commonly associated with a host of serious side effects including sleepiness, constipation, increased appetite and weight (Matson and Hess 2011; Posey et al. 2008). Osvaldo, for example, the 8-year-old child of Irene, completely lost the control of the urethral sphincter because of the long-term use of clonazepam, a drug sold in Portugal under the brand name of Rivotril, that he used as a tranquillizer for panic and movement disorders. When he eventually switched to risperidone, he had others unbearable side effects. Moreover, the use of psychoactive medicines instils in his mother quite conflicting feelings. Since drugs facilitate Osvaldo's social inclusion because their "sedative" effect, Irene feels that she and the educators used them in a way as instruments to "control" Osvaldo in social contexts such as home, schools and public space. When she shared her feelings of guilt and fear for probably doing violence to her son for the sake of enhancing his social performance and functional adaptation to mainstream society, some parents encouraged her to find some "good behavioural therapists" while others - mainly elderly parents of adolescent or adult with autism - warned her how maladaptive behaviours and irritability will be particularly dramatic when Osvaldo will grow up as she will no longer have the physical force to deal with.

Some of the topics that parents share in *Os Amantes de Saturno* could generate controversy and result in an intense debate. This was the case, for example, of some parents advertising about autism unconventional treatments. Beatriz, a 29-year-old desk clerk of a 4-year-old son named Joaquim, once communicates to the group her son's experience with yoga and reiki therapies, which she wrote, "are doing a better job than drugs". Some parents, especially mothers, reproached her of wasting her money on useless therapies and eventually exposing her son to some health risks. One mother even bantered Beatriz of being a patsy and susceptible mother and wrote to her: "you seem one of those mothers capable of healing your son with bleach". Diogo, the administrator of the group, and other users who intervened in the debate immediately reproached the attitude of the woman. As I later found out, she was referring to a "miracle cure" called Miracle Mineral Solution-MMS³⁵ invented by Jim Humble and described by the FDA (Federal Drugs Administration) as "industrial bleach". In Portugal, where the MMS protocol has spread thanks to its great success in the Brazilian market, several parents denounced its circulation to the DGS - *Direção Geral de Saúde* (General Direction of Health). Another unconventional treatment that usually engenders controvert opinions regards the use of cannabinoids. The first time I heard about the topic was during a discussion between Olga and Manuel at their home. Husband and wife were teasing each other about the possibility of using the CBD³⁶ (cannabidiol) contained in hemp oil for their 11-year-old son Ernesto. While Manuel did not want to take the "risk" and confessed his own concerns about the possibility of something going wrong, Olga defiantly argued how parents usually trust psychiatric medications just because they are legalized drugs:

"for a substance be legalized, we assume that the assumption is safe, but it's not always like that (...) honestly, I'm more afraid of risperidone rather than of cannabis, just because it's illegal it doesn't mean that it is not good for my child".

³⁵ The name MMS was coined by Jim Humble in 2006 in his self-published book titled: "The Miracle Mineral Solution of the 21st Century". MMS is a 28% solution of sodium chlorite (NaClO₂), a compound usually employed as bleach in paper manufacture. Before ingestion, MMS must be "activated" with lemon juice (citric acid), leading to the formation of chlorine dioxide (ClO₂), a potent oxidant used also as an industrial disinfectant. Its formula is very similar to the bleach we commonly use at home, namely sodium hypochlorite (NaClO). For a critical review see <https://www.theguardian.com/science/2010/sep/15/miracle-mineral-solutions-mms-bleach>.

³⁶ Hemp and marijuana belong to the Cannabis plant genus. Hemp differs in that it has very little THC (tetra hydrocannabinol) and higher amounts of CBD (cannabidiol). High amounts of THC are associated with marijuana's well-known euphoria. As CBD lacks the THC's psychoactive "high", many proponents advocate for the pediatric use of hemp oil. In Portugal, while hemp seeds' oil is relatively cheap (50ml for ± €10) and easy to order online, the CBD oil is more expensive (10 ml for ± €30) and can be only ordered from Spain-based online sites, which sell also cannabinoid-related products.

Her husband ironically ends the conversation saying something like: “today people can get whatever they want! You can buy something from the other side of the world at a distance of one-click”. Olga showed me some online forums, YouTube videos, and personal blogs where parents share stories about the positive result of the use of this substance in the treatment of hypersensitivity (to physical sensations, noises, smells) and hyperactivity associated with autism. In a well-known website dedicated to the therapeutic use of cannabinoid, parents advocate for its pediatric use and enthusiastically refer to hemp as “the hero we need” or “the compassionate care” (<http://asdconnection.com>). The biomedical use of cannabinoids for the ASDs treatment sought also the interest of the biomedical environment. Already in 2003, Rimland published a collection of anecdotal stories from parents who positively reported some progress with the use of cannabinoids, a report which did not contain however any references to statistical studies (Rimland 2003). More recently, scholars have advanced some results about the role of the cannabinoid as a potential therapeutic target for the pharmacological management of autism care (Chakrabarti et al. 2015; Siniscalco et al. 2013) while other authors prefer to be cautious (Bou Khalil 2012; Hadland, Knight, and Harris 2015).

Equally controversial is parents’ opinion regarding a cure for autism. As I have already outlined in Chapter I, the idea that people with autism could recover first took with Lovaas, the pioneer of ABA therapy. Lovaas declared to be able to recover “autistic pre-schoolers” with more than 40 hours a week of one-on-one of ABA therapy, by using a highly structured regimen of prompts, rewards and punishments to reinforce certain behaviours and “extinguish” others. ABA approach presented some methodological problems (low threshold of recovery and children’s average I.Q.), and the therapy itself was also criticised as it relied on “aversive”: sharp noises, slaps and even electric shock (this latter completely abandoned by the 1990s). Although some symptoms could become less severe with adulthood, the consensus has always been that autism core symptoms remain. Most instances of apparent cures are generally said to have occurred because of misdiagnosis or reducing deficits to the point of losing the diagnosis, in the sense that autism remains but the person has developed so good coping techniques that she acts as a neurotypical. All the parents I encountered, but especially those whose children show severe symptoms and co-morbid conditions, denied the idea that their children or young adults children can “recover from autism”. For these parents, autism does not have a cure because it is not a disease but rather a lifelong disorder and only behavioural and occupational therapies can help their children to adapt to the external social environment. The deny of autism’s cure is usually traced back to the neurodiversity approach according to which autism

is not a disorder but a diverse neurological variation. A radical fringe of this approach is represented by Ari Ne’eman, the president of the Autistic Self Advocacy Network (ASAN), for whom “autism is not as an illness in need of a cure” and thus should be accepted, embraced and accommodated³⁷. He even condemned the use of behavioural therapies for ethical reasons as they aim at changing the way autistic people think and interact with the world. The aversion of the neurodiversity movement to behavioural therapies derives also from the idea that they respond to society’s wish to “eradicate” autism, which dramatically reminds the methods used to change sexual orientation. Indeed, during the 1960s and ‘70s, Lovaas also used ABA therapy to cure boys showing so-called “deviant sex-role behaviours” (Rekers and Lovaas 1974)³⁸. Despite having succeeded in opposing negative stereotypes of autism resulting from an obdurate paternalism and a pathological view of neurological difference, the neurodiversity movement has also raised discontent. With reference to my fieldwork, those parents whose children show severe symptoms disagree with neurodiversity claims because of its restricted idea of autism as a “normal neurological variation”. Also, the biomedical environment denies a cure for autism. In this regard, those researchers who allegedly provide an evidence of autistic people who no longer meet criteria for ASDs (a trajectory called “optimal outcome”) have considered in their study only children and young individuals with high-functioning autism (HFA) with at least an average I.Q. (Fein et al. 2013; Fitch, Fein, and Eigsti 2015; Orinstein et al. 2015; Troyb et al. 2014).

Inside *Os Amantes de Saturno* group, the “autism cure” debate intensified following the increasing dissemination of the Son-Rise program, an interventional method especially targeted for infantile population that emphasizes the role of parents in developing their children’s social abilities. Some parents, such as Ivo, Zelia, Barbara, Beatriz and Helena, publicly and strongly accused the Son-Rise program to manipulate families by promising that autism is finally curable and fully recoverable. From my own experience speaking with parents, I think that what more outrages them is the idea that Son-Rise supporters expressively “go hunting” parents who are

³⁷ In 2009 President Obama endorsed the nomination of Ne’eman to be a member of the National Council on Disability. While some welcomed him as the first person with autism to serve the Council, others claimed that he could not represent the diverse range of people diagnosed with autism. Ne’eman’s nomination was eventually confirmed by the USA Senate in July 2010 and he served the National Council on Disability until 2015.

³⁸ The study shows how Lovaas, who at the time was principal investigator for the NIMH-funded Feminine Boy Project, and Rekers (one of his favourite doctoral student) treated a 4-year-old boy called Kraig diagnosed with a “swishy” gait and an aversion to “masculine activities”. Lovaas rewarded “masculine” behaviours and punished any “feminine” behaviours showed by the little boy, and eventually considered ABA treatment a success when the boy looked “indistinguishable” from his peers. Years later, Kraig came out as gay, and at 38 he committed suicide, cf. <http://edition.cnn.com/2011/US/06/07/sissy.boy.experiment/>.

desperate for hope. Also, Ivo and Barbara blamed the association promoting the program *Vencer Autismo* (Defeat Autism) for its *modus operandi*, namely a “pyramid business model”. Son-Rise advertising consists, indeed, in offering some free lectures in order to attract parents and then in proposing a 5-days-training at the cost of €1200. Beyond the economic investment, the Son-Rise program prescribes to children and parents an intensive involvement of at least 20 hours a week up to 40 hours a week, forcing parents to face psychological, working and financial efforts and implying for children a deep alteration of their regular school schedule. Disagreements and accusations escalated. Diogo had to moderate the tone of the discussion thread several times, especially when parents who support the Son-Rise posted some advertising or shared the videotaped history of their children’s “recovering from autism” as proof of the validity of the program. Similarly, Beatriz shared with the group a statement of the president of a Portuguese association called AMA - *Associação de Amigos do Autismo* (Autism Friends Association) who wrote: “it is totally inappropriate and unseemly to ask parents large amounts of money to obtain training and information on how to ‘cure’ and ‘fully recover’ from autism because this means to charge them with the responsibility for the program’s results”. Quickly, the Son-Rise supporter parents belonging to the *Os Amantes de Saturno* unfollow the AMA Facebook page and even withdrew their own friendship to some parents of the group.

By providing information and debating around some controversial topics regarding autism therapy and classification, parents are also sharing their personal experiences with their children and the challenges that they faced every day. Complicity and mutual understanding are fundamental in supporting parents’ disappointment and frustrations as well as in helping them to overcome false expectations. As Olga argued:

“I think I will never stop dreaming about my son... I know that he will probably never be an autonomous person, and because of that I mourn every day with the help of other parents. You know those parents [members of *Os Amantes de Saturno*] are the most loyal and honest friends that I could ever have, they are better than my family who even accused me of not knowing how to deal with my child, you cannot imagine how it hurts! every child is evolving in her own terms and times and only parents like me could really understand this (...) it’s thanks to them that I haven’t given up”.

In what follows, I will finally address parents' stories of living and caring with a child with autism by identifying four central matters, such as dealing with challenging behaviour, coping with other people's judgment, lack of support, and autism's impact upon the family.

In a support group, parents seek personal advice in regard to how to deal with their children's challenging behaviours, such as highly routinized behaviour, negative reactions to direct orders, disapproval and routine change. These situations make parenting particularly demanding and difficult and led parents to question their own parenting skills. For example, Olga uses to write in a diary the minutiae of her quotidian with Ernesto to understand which pattern in her or his son's behaviour or what routine change could cause her son's recurrent meltdowns. Meltdowns and tantrums could be, indeed, a reaction to frustration, to the inability to react appropriately to some situation, or even to the failure to be understood by others. In this respect, I remember an episode occurred once Olga invited me at lunch at her house. When she told Ernesto to sit down at the table, he pushed the plate away and quickly took off her glasses pulling her hair once she tried to take them back. After having puzzled over the reasons for that reaction, she finally concludes that he probably felt uncomfortable to eat with metal cutlery as a host (me) was invited at home. Indeed, at mealtimes, Ernesto is used to eating with silicone cutlery, he is the first to be served and gets nervous if the mother cuts the meat or blows on his soup. Sometimes thus his tantrum is as a way to communicate something, to express discomfort or a refusal. Olga gently explained me how for Ernesto it was not easy to cope with my presence in a so intimate environment like home.

Some ordinary activities or situations - such as a queue at the supermarket, the morning toilet routine or food textures - reveal to be very problematical for parents to manage both emotionally and practically. *Os Amantes de Saturno* represents in this sense a safe place where parents share their experiences in order to ask for hands-on advice. Irene, for example, wrote how she needed to unburden her frustration and sadness by sharing with the group her experience with some customers at the supermarket. About ten parents urged her to vent out. Apparently, some costumers suspected about her honesty when she asked the cashier to skip the queue, as Osvaldo seemed impatient and she was afraid of a possible violent reaction. A meltdown into a supermarket due to a loud noise or too bright light could result in Osvaldo screaming and kicking her. She wrote how emotionally intense was to hear the customers whispering something about her. She received comments of encouragements while some parents accused the costumers of coldness and indifference. Diogo, as usual, toned down the conversation: "This

happened not because people are mean, but because autism is invisible at sight!” and suggested Irene to try to patiently sensitize strangers in future similar situations and to never take strangers’ suspicions, doubts or hesitations as personal allegations. This exchange of experiences is important to encourage parents not to give up to daily difficulties, as well as to find creative solutions to face people’s curiosity or mistrusted stares. Sharing is fundamental for parents also to compare each other educational strategies. Luisa and Diogo for example compare the methods they used to encourage self-sufficiency in their children by mapping the clothes of their room with pictures - namely by sticking pants and t-shirt pictures on the closet or underwear and socks pictures on the nightstand drawer. This technique enables their children to autonomously choose each day what they want to wear. Similarly, as most children with autism appear to have sleep issues, a Beatriz shares with the group a video tutorial on how to make a large and sturdy U-shaped pillow that allows children to wrap them inside and feel like it was a reassuring hug. By sharing these simple and ordinary suggestions, parents are mutually learning from each other, feeling they are not alone, and reinforcing a feeling of community.

Parents often have difficulties in dealing with their children’s hypersensitivity or morning hygiene routine. Helena, for instance, struggles as his son Vasco has some sensory issues with regard to food textures and cutlery’s material. He eats only salmon as fish food, vegetables have to be reduced in puree, the spoon cannot touch his mouth so that he took the habits to keep on tilts his head in order to the soup falling directly into his mouth. The same happened with his oral hygiene. As for many other people with autism, also for Vasco vibration and brushing are uncomfortable or painful sensations. These difficulties deeply affect Helena’s daily routine at home, especially because Vasco is now a 15 years old boy. She often shared some video showing Vasco’s progress and efforts in expanding his abilities to cope with his own sensitive issues. People with autism may feel the touch, smells, a shining light or a loud or noisy sound as unpleasant phenomenological experiences that aroused very strong reactions. This trait is understood as an excessive sensory response to external stimuli, from which a person with autism may feel the need to move away. These sensory issues turn a person with autism into a *perceptive par excellence*. In this respect, I will report some field notes about my encounter with Oscar and Laura:

“We are in this quite huge park and Oscar has taken a cobble and started to caress his face with it as if his skin could vehicle its cold smoothness. Then he has started to do the same thing to

me; he has touched my face and my arm with the stone or maybe through it. I refuse to think that he is not aware of me...I was there”.

I have later looked critically to my perhaps naïve view about the meaning of the sensorial encounter between Oscar and me. I was worried about constructing the idea of Oscar as having a different relationship with the materiality of my bodily presence only because I was thrilled by the possibility to explore a kind of “in-flesh encounter” with a non-verbal child. Actually, I had so many expectations about my supposed ability to be an open-minded anthropologist that I feared to interpret as a resonating sensitive encounter something that was nothing more than a simple game with a cobble. But yet that simple contact had a meaning that went beyond its appearance. Oscar was interested in playing with me and he communicated his will by approaching me with a cobble. My presence did not bother or disturb him, and that simple fact just meant a lot to me. These considerations help me to acknowledge my own fascination for the supposed “enigmatic character” of children with autism and my anxiety in succeeding to get close to both parents and their children. At the same time, I am compelled to taking into account how the sympathy I felt for my interlocutors has positively affected our relationships. I feel that, while gradually gaining their confidence and trust during the fieldwork, I was also proving them that I was not just interested in their stories but that I became “*sensitive*” to their struggles. And this has represented an important matter for parents that have accepted my presence in a group where they exposed their intimacy and personal difficulties. This sense of reliability and confidence is crucial for parents as they often consider the community as a second family where building and maintaining positive and supportive friendships. Many parents who participate in online support and advocacy groups personally know each other. They often mention each other by using “tags”, a Facebook tool that notifies a user when she is referred to in a post. Those parents who live in the same area of residence usually go out together or organize their holidays with the respective families.

So far, I showed how “asking to the group” represents a way for parents to easily and directly ask for and receive support, advice, help and encouragement. In his regard, due to the high demands associated with taking care of the child, parents often vent about the feeling of being “absorbed into their children’s autism”. ASDs as a long-life condition has “deep implications on parents as they are faced with a range of challenges and emotional consequences in raising the child” (Ooi et al. 2016:746). Intensive care often forced parents to neglect the other siblings (Meirsschaut, Roeyers, and Warreyn 2010; Myers, Mackintosh, and Goin-Kochel 2009:679),

arousing feeling of guilt. Full-time care is particularly dramatic for single parents and women, who are generally those who quit the job in order to become the primary caregiver (Anderson 2009; Gray 2003). Also, it arouses some socialization restriction for the whole family. This happens not only because parents do not have so much time for friends but also because of the unpredictability of autistic children's behaviour. As the accident at Olga's home illustrates, parents are often worried about making a wrong move, to say or do something that can trigger the child with unpredictable consequences. My encounter with Laura shows how this unpredictability could be also dangerous.

As we walked out of the metro station, Laura was always holding Oscar in her arms. Despite Oscar was already 4 years-old and Laura seemed fatigued, she couldn't bear the thought of losing her son. The unpredictability of Oscar behaviours forces his mother to constantly focus on him, to always be - as she said - "in alert mode". Oscar likes to run away on the street, so Laura feels the pressure to "always keep an eye on him, always, like a watchful eye". I first believed that Laura was too anxious or apprehensive towards her son until I personally experienced what does she means with that "alert mode". I proposed her to have a coffee in a near park where Oscar could maybe have some fun and she could rest. We were seated in one of the outside tables attached to the coffee bar when Laura asked me if I could stay with Oscar while she went to buy cigarettes at a near tobacco shop. It was the first time I could stay alone with him and I was more intrigued than worried about that. But as soon as I found myself alone with Oscar, Laura's stories about his unexpected escapes bombed in my head. While I was trying to keep calm and confident before Oscar's eyes, I felt uncomfortable and apprehensive: I waited so intensively for Laura to come back! I wrote some personal notes after this episode to help me venting my tension: "she first scared me and then she leaves me alone with him? Did she like to complain? I don't want to judge her, but she behaved so negligently, she knows that I'm not a therapist nor a teacher, I have had any idea what to do if something happened!" These scribbled handwritten notes prove that I was just coming to terms with the reality of the fieldwork, with my expectations and fears. But they also show how difficult is to emotionally cope with some features of autism.

Behavioural difficulties could arouse a sense of discomfort, especially in the social context when parents are facing the presence of strange people. In this aspect, parents of disabled children are more likely subjected to be judged by others, which sometimes exacerbates the sense of non-acceptance of the diagnosis and results in self-marginalization (Blackledge and

Hayes 2006; Safe, Joosten, and Molineux 2012). The relation with the broader social context and the experience of the others' gaze as well as the feeling of social stigma are crucial issues in parents' personal accounts of their parenting experiences. In this regard, the simple utterance of the word autism creates in parents an unprecedented anguish, especially when in the public space. Autism is not a physically visible condition, like Down syndrome for example, and many children may perfectly communicate despite some difficulty in interaction. Moreover, some of them might not show typical autistic features like stimming, which usually refers to specific behaviours that include hand-flapping, rocking back and forth, repetition of words and phrases, repetitive blinking or moving fingers in front of eyes. There are still preconceived ideas about what autism looks like and common people did not generally realize that autism could manifest in variable ways.

As an illustration, when describing their impressions and feelings about going out with their autistic children, parents often use words and expressions highlighting the emotional and bodily quality of these experiences. On one hand, the majority of mothers frequently describe the sensation of being "watched" by others by expressions that show guilt and shame. They felt morally judged by others because of their child's behaviour or because of their inability to take care of the child, which sometimes provoke in them the "desire to physically disappear". On the contrary, fathers are likely to react in a more positive way, as Pedro once said to me simulating an imaginary discussion with someone in a public space: "It is like in Western movies, I look straight in his eye, you know? You have to understand me; I don't yield to your ignorance. It's not me that has to go away, what do you think? If you do not like my child's screams or his weird noises...go and look for another place!". This difference is likely due to the fact that mothers are socially expected to take all the responsibility for parenting, so that they are usually considered more responsible than fathers about their child's manners. As a result, social stigma discourages or reversely stimulates parents' efforts to "socialize autism" out of the private space of the home. As other stranger people may not be properly informed about "what autism is like", parents often told that their children are treated as "ill-mannered children" or "poor creatures". Because of these misleading representations, parents fight for a widespread and deeper understanding of disability issues. Raising autism awareness is also for them a way to alleviate the emotional impact that social stigma in public space have in their daily lives.

Chapter IV

Parents' advocacy for social change

In this chapter, I will describe parents' advocacy regarding issues that are specific to school and post-childhood period (adolescence, sexuality). In doing so, I will explore the temporal nature of advocacy practices by showing how parents' social demands and political claims change over the time and explore in more details some of the topics that I have discussed with parents with regard to transition to adulthood, such as social services for adult autistic people, living arrangement, recognition of legal capacity, sheltered employment, infantilization and long-term life plan. Finally, I will argue how parents' personal engagement in autism advocacy changed their subjectivity as citizens and turning thus advocacy as a tool not only to raise public awareness about autism but also to affect society at large.

From school to adult life

Advocating for autism awareness and social inclusion

The daily difficulties and efforts of living and taking care of a family member with autism led parents to campaign for a better understanding of autism in order to challenge social stigma and indifference. The worried but still confident inflexions of parents' voice, the tired but proud expressions of their faces disclose the concreteness of their experiences and thoughts. Parents also advocate on their children' behalf in order to receive support, as well as health and educational services (Hall and Graff 2010; Markoulakis et al. 2012). In this section of the chapter, I will then present some of the issues reported by parents as examples of their involvement as their children's advocates.

Several scholars investigated how school and college communities foster the learning and development of autistic young people (Prince-Hughes 2002), connect people with autism with the rest of the community, and contribute to social inclusion thanks to their "team-like approach" (Baker and Welkowitz 2005). This is why, one of the most urgent campaigns led by activist parents concerns the social inclusion of their children in the educational system. Non-verbal communication, communication impairments (such as difficulties in decoding a sentence) and some struggles in social interaction (due to autistic children's difficulties in adjusting behavior to social circumstances) could deeply affect school performance and

inclusion. In May 2015 by the *Observatório da Deficiência e Direitos Humanos* (ODDH - Disability and Human Rights Observatory) condemned Portugal failure to implement inclusive education legislation and confirmed how regular schools for disabled children still lack adequate human resources and structural means³⁹. In a later interview at national channel RTP, Paula Campos Pinto⁴⁰ - coordinator of the ODDH and supervisor of the *Mecanismo Nacional de Monitorização para a Implementação da Convenção sobre os Direitos das Pessoas com Deficiência* (National Monitoring Mechanism for the Implementation of the Convention on the Rights of Persons with Disabilities) - declared how the situation was going to compromise the educational and social future of the young population by turning social inclusion a mere physical inclusion or by creating an institutional “resistance to inclusion” enacted even by the families of children with disabilities who eventually prefer to enroll their children in private institutions. After Prof. Pinto declarations, Zelia emphasised parent advocacy’s role in a post on *Os Amantes de Saturno* page that raise incredible support: “as activist parents we will continue our struggle for the inclusion of our children because this “resistance to inclusion” blatantly violates the rights of these children and young people, this doesn’t scare us!”

The dramatic situation conveyed by the ODDH report derives from the financial measures that Portugal adopted after the financial crisis of 2007–2008 which made the country unable to repay or refinance its government debt. Following other European countries that also went into debt crisis⁴¹, in 2011 Portugal applied for bailout programs from the International Monetary Fund (IMF) the European Commission (EC) and the European Central Bank (ECB) in order to prevent an insolvency situation. The Troika⁴² aimed at monitoring the commitments that Portuguese authorities should accomplish to receive the international financial loans provided for by the EU and the IMF for the reduction of economic indebtedness and debt restructuring. On the contrary, this resulted in austerity measures and reforms in different sectors among which housing market (both in the lease and credit purchase), transport, salary adjustment, tax

³⁹ <http://oddh.iscsp.utl.pt/index.php/pt/mediateca/imprensa/item/176-escolas-regulares-não-têm-recursos-para-crianças-com-deficiência-observatório>.

⁴⁰ Paula Campos Pinto is Professor at the *Centro de Administração e Políticas Públicas* (CAPP) of the ISCSP and representative in Portugal of the ANED (Academic Network of Experts on Disability). Cf. RTP interview www.rtp.pt/noticias/pais/observatorio-da-deficiencia-aponta-o-dedo-as-escolas_v833244.

⁴¹ By the end of 2009, the Greek economy faced its most-severe crisis, followed by Ireland in 2010, Portugal in May 2011 and Cyprus in April 2013. Spain and Italy were not officially obliged to Troika’s demands but forced into austerity through reforms and financial measures.

⁴² Troika is the name assigned to the team formed by the International Monetary Fund (IMF), the European Commission (EC) and the European Central Bank (ECB). The name originates from the Russian word troika, which originally refers to the Russian word for a carriage with three horses and it used to designate any type of collaboration or committee of three members.

burden, exportations taxes, pension, education, and National Health Service. Although Portugal left the aid program in May 2014, these measures continue to affect families' social and economic conditions.

Several Portuguese disability scholars already drew attention - even before the Troika's measures took place - to the structural framework of inequality faced by people with disabilities, such as "lower levels of education, lower employability and lower labor income, and higher health expenditures" (Portugal et al. 2010:277). These authors argued that Portuguese welfare and social aid have a mere compensatory value since they fail to provide both special educational services and health care. This eventually led families with autistic children to spend between €12,000 and €13,000 per year (idem: 223-24). Since 2008 then, austerity measures have resulted in a further considerable reduction of the resources allocated to disability programs and services, particularly 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). These considerations deny the idea of autism as a burden for public healthcare budget; an idea mainly based on a paternalistic and stereotyped assumption that sees families as subjects recklessly and numbly dependent on welfare in order to take advantage of public assistance. In this respect, mothers are particularly harassed by the misleading opinion that since they work less, they, therefore, purchase large packages of services (Waltz 2015:353). In Portugal, households bear almost entirely the economic costs associated with ASDs and only a few obtain the services on which the estimates are actually based. The National Health System (*Sistema Nacional de Saúde* - SNS) does not always provide, for instance, speech and behavioural therapies nor they are eligible for reimbursement. According to a national study about the quality of life of families with autistic relatives up to 25 years old (Nogueira et al. 2014), Portuguese families spend an average of €371 per month for medical expenditures and therapies and less than a half is eventually refunded. Many parents I interviewed, for example, cannot afford some specific therapies (such as hippo-therapy and speech or occupational therapy), affecting in this way the possibility for their children to improve communicative and relational abilities. Moreover, the expense of autism represents a variety of direct and indirect costs, from medical care to special education to lost parental productivity, affecting negatively both family income and quality of life. In this respect, the study reveals that the "social costs" of autism considerably affect family's leisure activities and parents' employment, being that 23% of parents preferred to work

part-time in order to care for their children, while other 70% (mainly women) left their personal career.

To further understand the impact of public cut funding on special education programs, I once published in *Os Amantes de Saturno* a video entitled *Crianças com necessidades especiais com apoios cada vez mais reduzidos* (Children with special needs with increasingly reduced social aids) produced by the TV channel *SIC Notícias* in June 2015⁴³. The reactions within the group were particularly taut. The reduction of the social security budget resulted in the introduction of more restrictive eligibility criteria to request social aids (Portugal 2016). In this regard, the case of Zelia is sadly emblematic. Because of the reduction of the resources allocated to home support service and since his son did not yet reach 16-year-old - the age range necessary to be eligible for the CAO (Center for Occupational Activities) - Zelia was obliged to ask for a part-time librarian position in order to assist in-home her 13-year-old son Leandro after school. Despite her now lower income, she did no longer meet the criteria to demand free home-school transport or free school meals. Her situation proves how the economic crisis and the Troika's austerity measures in Portugal had a significant and negative impact on the lives of people with disabilities, on the effective realization of their rights, and on their parents' life and job conditions. For instance, parents' right to a day of leave at work to provide assistance to a person (regardless her age) with a disability or a chronic illness is also limited to up to 30 days a year or during the entire period of hospitalization and cannot be exercised simultaneously by the two parents⁴⁴. Service public providers have (negatively) complied with this already dramatic situation. "The legislative measures - said Zelia - have changed the procedures for requesting the educational services...and this just ends up with us parents completely trapped within the bureaucracy of the different ministries passing each other the buck on who is supposed to provide the service".

Parents' indignation exploded during the Portuguese legislative elections campaign of 2015 (from September 20th to October 2nd, 2015) for the Assembly of the Republic. The circumstance was a meeting - *Uma Agenda para a Inclusão de Pessoas com Deficiência ou Incapacidade* (An Agenda for the Inclusion of People with Disability or Incapacity - 25th September 2015) promoted by the Socialist Party, who called parents to participate. The socialist leader Antonio Costa and Ana Sofia Antunes, candidate in the district of Lisbon and a blind person, had

⁴³ See here https://www.youtube.com/watch?v=bCnV_s8_Fe0&feature=player_embedded

⁴⁴ See <http://escritosdispersos.blogs.sapo.pt/416522.html> and <http://cite.gov.pt/pt/acite/dirdevtrab.html>

declared their will to pursuing equal opportunities for all citizens and to acknowledge disability as a central concern of their political program. Since I could not attend the event, I have asked parents to share their commentaries, which eventually conveyed different ways of conceiving and approaching politics. Some parents, indeed, argued that the “renewed” interest in disability-related issues during the election campaign was a form of pork barrel politics, with political leaders trying to please voters to win votes for their own personal advantage. Other parents, on the contrary, considered an alliance with politics of vital importance and supported local and national political representatives. In this way, they aimed at gaining visibility to the autism advocacy movement and to disability issues within the Parliament and the larger public opinion.

Social and economic factors have, hence, a significant impact on disabled people’s life and they result - as parents argue - in social exclusion and civil rights denial that - by pervading the daily life - often normalize certain practices. I will recall, in this regard, the experience of Raquel who is one of the founders and board member of *Dar Resposta*⁴⁵ (Give an Answer) a “movement of parents, family and friends of citizens with disabilities” and a mother of a 13 years old boy with autism, Fernando. She compared, for instance, the holiday camps targeted only for children with SEN with the ghettos: “they are like the warehouses, there is no inclusion and children are segregated from the rest of the young people of their age”. Actually, a holiday camp aspires to be a place where all children can play and stay with everyone. Unfortunately, for children with SEN the vacation does not represent a shared experience of socialization with other children but rather “another week of specific activities promoted exclusively for children with multi-disabilities, autism or Down syndrome”. According to this activist mother, this represents a setback in the journey towards full inclusion, betraying her view of a society aiming at promoting equal opportunities and enhancing the quality of life of people with autism. Raquel claims that the reasons behind this state of things are essentially political and cultural; common people - she said - “don’t even envisage the possibility that people who are different from them could have the same rights, they don’t even wonder whether these children and young people desire to access this world and its opportunities”. Holiday camps could even refuse to enroll a child with SEN, under the guise of not having inadequate infrastructures or low-skilled human resources to address the needs of these children and ensure their well-being. For Raquel, on the contrary, the adaptation of their business plan to the specific needs of disabled children represents for these entities an unprofitable measure.

⁴⁵ <http://darresposta.com>

As shown by the above examples, denouncing practices of exclusion is a crucial purpose of parents' advocacy. The public petition is, in this respect, one of the instruments used by parents to effectively turn their ideas and demands into action. In general terms, a petition gives clout to issues that could otherwise go overlooked by government. A petition is generally used to change a law or to raise awareness for an issue; it is an easy, approachable and low-cost way to get the word out by seeking for public support. Online petitions allow people who believe in specific causes to mobilize the broader population, as well as to draw mainstream media attention to a particular issue. An online petition platform can, at this regard, measure public engagement and sentiment for a particular cause. Slogans as “be part of the change”, “the time has come to do something” and “your contribution is critical” are fundamental to attract other people and to push them to commit to a cause. In Portugal the most popular free online petition service is *peticaopublica.com*, a platform mostly used also by the parents I encountered in my fieldwork. This online platform, like many other ones, allows people to create a petition, to share it and to search for people to sign it. Parents especially use this instrument to pressure on State with regards to disability and autism-related issues, to raise awareness about specific topics, and to organize a protest.

During my fieldwork, the first public petition designed by parents aimed at raising public concern over bullying⁴⁶. Bullying represents, indeed, a sensitive issue especially when committed against disabled children and young pupils at the school. Within the *Os Amantes de Saturno*, Olga started a discussion thread about the topic in order to collect parents' accounts about the impacts of bullying over their children. After expressing my interest in the topic, Olga replied to me with a private message describing an episode that made her feel sad and disappointed and that pushed her to sign the petition:

“some guys at school have made me mad, they have spit on my son [Ernesto] when he was just trying to interact with them...those young boys who even attend Scouting and catechesis! They crossed the line and I dealt with them! Teachers should take a cue from these incidents and report them during class lessons to get students' attention, why did they do this? Just to enjoy? One of them is a schoolmate of Lara [Ernesto's sister] and he has already noticed that Ernesto was “different” (...) luckily some other kids alerted me that these two boors were spitting on

⁴⁶ In 2010, a public bill aimed at establishing a so-called “crime of school violence”, which was not applicable anyway to minors. Despite in Portugal both bullying and school violence are not considered specific crimes, there are different legal instruments to address the phenomenon. For a review on the subject cf. *O Bullying e a Lei at Educare - O Portal da Educação* <http://www.educare.pt/opiniaio/artigo/ver/?id=37843>.

him! They really crossed the line! I scolded them in front of the teachers and other parents, in front of all those who were there and said that they didn't see anything, but then I got angry with myself, it hurts, it still hurts!"

Olga's words are dramatic for different reasons. First, disabled children are more likely to be bullied than most other groups of children. Second, bullying is a form of violence and subjugation has serious and detrimental impact on children's lives and on their self-esteem, affecting both peer relations and friendships. Finally, Olga's outburst demonstrates how a parent deeply and intimately feels social injustice. Despite this touching experience Olga tried to overcome her fear. During a meeting we planned some days later the accident, she said:

"I have tried to not stifle him with my fear, I know that it could happen again to him... that someone could still hurt him. It is hard to push yourselves to let him go into the world, I don't want to protect him as he was a fragile sparrow chick, he needs to stay with his peers and every day I strive to live with my anxiety, my fear, with the terror that someone could take advantage of him (...) you have to leave your child out into the world even if it could hurt".

At the time of my research, the petition did not advance to a further step, but it generated a debate about the need to manage and stem the cases of bullying in schools. Debates and online discussions have an impact in spreading a message and questioning the social and political *status quo*. Often online petitions and debates represent the fuse of a process leading to active and passionate campaigning on the streets, which may result in the recognition by the political bodies of the importance of the subject. The right to petition represents, indeed, one of the fundamental rights of citizens vis-à-vis the political power, and it is guaranteed by the Article 52 of the Constitution of the Portuguese Republic (Chapter on rights, freedoms and guarantees of political participation) and regulated by the Article 232 of the Procedures Rules of the Portuguese Parliament⁴⁷. According to these legislative measures, when a petition gets over 1,000 signatures it gets published in the *Diário da República* (Official Gazette), while if more than 4,000 citizens subscribe it the Parliament is expected to debate the issue in a plenary session. As a result, the more people sign-up an online petition the more likely the government is called to respond to citizens' demands or is made accountable for a specific issue.

⁴⁷ For further information about current Portuguese legislation cf. www.peticaopublica.com/info/legislation.aspx; www.parlamento.pt/EspacoCidadao/Paginas/Peticoes.aspx; www.parlamento.pt/Legislacao/Documents/Legislacao_Anotada/ExercicioDireitoPeticao_Simples.pdf; To know more about how to apply for a petition cf. www.peticaopublica.com/info/help.aspx; www.parlamento.pt/EspacoCidadao/Paginas/ProcedimentosApresentacaoPeticao.aspx.

Albeit some online petitions might not even bring significant change, the Internet represent a good platform for getting the word out and for more effective, active and passionate campaigning. This was the case of another online petition launched in January 2015 by the *Associação de Pais pela Inclusão* (Association of Parents for the Inclusion) that I have personally signed and whereof attended the debate. The petition asked the revision of an ordinance - *Portaria n. 275-A/2012*⁴⁸ - that regulates the transition to after-school life for pupils with special educational needs with more than 15 years of age who have attended elementary school with a specific individual curriculum (CIS). According to this law, students with SEN who meet the above criteria should attend school no more than five hours per week and have to fulfil the remaining twenty hours of schooling in specific vocational training programs provided by public or private institutions. I received an invitation to sign the petition from Raquel for whom the Ordinance was likely to allow institutionalization without parents' authorization and prevents students with SEN from socializing and growing with their peers, denying their right to compulsory school till 18 years old. The FENPROF (the National Federation of Teachers) gave also voice to teachers' indignation against a law that discriminate disabled students and joined the parents in this protest. In few weeks the petition reached a high number of subscriptions and the Parliament agreed to debate the petition in a plenary session at the beginning of February 2015. Some parents and I planned to meet at half past two in the afternoon in front of the neoclassical *Palácio de São Bento* (Palace of Saint Benedict), the seat of Portuguese Parliament. After passing through security, we eventually gained the access of the central hall from where the slight hum of deputies' talks climbed up to the upper gallery, consisting of 3 separate sections of benches. Once the session began, Raquel and the other parents (all women) were really impatient, waiting for the Parliament to discuss the petition's topic, which was eventually scheduled as the last item of the agenda. Finally, a deputy of a left-wing party *Bloco de Esquerda* (Left Block) requested on the behalf of the petitioners the revocation of the abovementioned ordinance in order to prevent any disguised form of authorized institutionalization. The ordinance was actually the result of an earlier measure of funding cuts that from 2011 has gradually deprived the Ministry of Education (MEC) of around €70 millions. In August 2015 the MEC finally revoked the *Portaria 275-A* and entrusted the promotion of social inclusion for children with autism and other disabilities. As this case showed, despite the Special Education Law (Law 3/2008) defined principles, procedures,

⁴⁸ See <http://publicos.pt/documento/id351887/portaria-275-A/2012>.

programs and arrangements for special education implementation, the path for the social inclusion of children with autism is still long:

“whenever someone discriminates my child, I try to make her understand why and how she did wrong - said once Diogo - it’s too important to explain people the cruel effects of mockery, indifference, school exclusion...because within a lifetime this could leave people with autism and their families more and more ignored from the society they live in”

As I already mentioned, when public or private schools deny enrolling children with SEN or do not provide appropriate supports and services, parents have the legal right to file a discrimination complaint. Parents’ experiences of discrimination can powerfully become an opportunity for sharing knowledge with other parents who one day may find themselves in the same situation. For example, two days after we attended a training course at the INR (an episode I reported in Chapter III), Irene has already informed parents of the *Os Amantes de Saturno* group about how to file a complaint, to which public subject send it (i.e. the MEC-Ministry of Education, the IGE-General Inspection of Education or an ombudsman), and what legislative measures to mention (i.e. the Non-Discrimination Law 46/2006, the Special Education Law and the Dispatch 7-b/2015 on compulsory school’s enrolment conditions and class formation)⁴⁹. Irene believes that school environment represents the most sensitive places where discrimination takes place. She expressed, for instance, her anguish when parents of normally-developing children attending the same school of his son considered that he was receiving more consideration in the classroom in comparison to their children. This vision actually contributes to some misleading conceptions. It firstly transmits the idea of autistic children as a “burden” on the educational system, disguising discrimination and marginalization. Secondly, it dangerously implies that educational settings adapted to autism’s needs and special education teachers represent “privileges” rather than prerequisites for social inclusion. Sometimes, parents accused also school professionals of discrimination. Leandro, for instance, the 13-years-old son of Zelia, could not attend a guided tour at the Lisbon Planetarium because his special education teacher argued that “he would not understand anything”, showing - as Zelia said - “no sense of compassion for the child and no engagement with his role as a special teacher”. According to her, autistic children’s exclusion is often due to the lack of training and

⁴⁹ Non-Discrimination Law (Law 46/2006) http://www.inr.pt/bibliopac/diplomas/lei_46_2006.htm; Special Education Law (Law 3/2008) http://www.inr.pt/bibliopac/diplomas/dl_3_2008.htm; Dispatch 7-b/2015 https://www.portaldasescolas.pt/imageserver/plumtree/portal/matnet/DespachoNormativo_7B_2015.pdf.

“humanity” of special education teachers. She reported, for instance, how the same teacher once asked her to administer a sedative drug to Leandro, as he showed to not be able to sit quietly during lessons, bothering with his disruptive behaviour the other colleagues. As I mentioned before, some behaviours of autistic people are often difficult to dominate or to calm down, challenging teachers’ ability to keep the lesson going and leading parents of other students fear for their relatives’ safety⁵⁰. Actually, Leandro’s aggressive behaviours, which according to his mother represent “help requests”, collide very drastically with conventional patterns of social behaviour and communication. Whereas at first Zelia felt shocked by the teacher’s request, she lately understood her difficulties and struggles and eventually built a more cooperative relationship with her. While the scarcity of financial and human resources threatens special education services and supports and puts a strain on teachers, building school-family partnership strengthens mutual effort and contributes to the child’s school success and inclusion.

Parents have frequently warned that the education funding crisis risks transforming schools into discriminatory environments for students with SEN. This situation emerges, for instance, from Olga’s account about her son’s school context. Ernesto is, indeed, enrolled in a class of 25 students and just benefits from a half-hour of occupational therapy 2 days a week. Furthermore, he attends so-called *Unidades de Ensino Estruturado* - UEE (Structured Learning Units), which aim at promoting the participation of students with autism and other disabilities within the curricular activities and at implementing interdisciplinary methodologies to facilitate their learning, autonomy and adaptation to a regular school context. Since the UEE also envisages some specific activities, Ernesto does not always follow the same time schedule of his classmates who, according to Olga, seem “emotionally detached” from Ernesto, as well as from the other five students with SEN enrolled in the same school:

“they [Ernesto and the other students with SEN] don’t engage in the classroom mood, they lunch earlier and have extra time at recess, they are like strangers for their classmates (...) it’s very sad for me... a school is not inclusive just because enroll your child, this doesn’t mean that it’s a good school but rather [it is] a storage!”

⁵⁰ This episode reminded me the case of a 17-year-old boy with autism who was expelled from a school in Faro (a town in southern Portugal) after having assaulted a teacher and two female employees. The case gained the attention of the media also because the headmaster clarifies how the school actually did not have the human resources to guarantee a full-time assistant to the young boy.

A real program of social inclusion in educational settings - she once wrote me in a chat - rejects the use of “special” schools or programs, which inevitably separate students with disabilities from students without disabilities. During the fieldwork, only a few parents were satisfied by their children’s broader school environment, which was generally a private or a semi-private school with agreements protocol with the Ministry of Education. When protocols lack, parents can choose to “reinforce” the educational training of their children and hire private technicians.

To further understand the role of parental advocacy with regard to special education, it is worth understanding the specific curriculum programs available for pupils with SEN. Some parents like Raquel, Zelia and Helena, especially fight to guarantee their children a special curricular program called PEI *Programa Educativo Individual* (Individual Educational Program), which can be requested by directly addressing the school or the DGEstE (Directorate General of School Facilities). The PEI is an educational measure that responds to the specificity of each student’s needs by adapting teaching strategies and undergoes to different criteria of school performance’s evaluation. Most parents argue that the measure facilitates the development of their children’s specific skills allowing them to complete secondary education. On the contrary, the CEI - *Currículo específico individual* (Individual Specific Curriculum) is a more restrictive measure insofar as it presupposes significant changes in the school curriculum, with the substitution or even the elimination of certain objectives and contents. The adoption of this latter measure prevents students to follow the school transition regime and thus to pursue studies of higher academic level⁵¹.

A support and advocacy group such as *Os Amantes de Saturno* represents a crucial tool for parents to cope with the stress of dealing with the bureaucracy of different Ministries (education, health, social service). Considering the changing nature of the regulation of social care services and support, it is advantageous for parents to elucidate each other, for instance, about the procedures to follow in order to ask for tax benefits or other public financial aids (such as school meal allowance, free public transport, schoolbooks, coverage or reduced cost to purchase assistive technologies). As an illustration, the special education allowance - available for disabled people under the age of 24 and covering just the school months (from September to June) - helps families to purchase specialized therapies that regular schools were not able to provide. Its amount, determined by household income, do not exceed €3,000 per

⁵¹ www.educacaoespecial9.webnode.pt/products/o-que-e-o-cei-curriculo-especifico-individual/

year (Segurança Social 2017a) and it cannot accumulate nor with social disability pension either with the so-called 3rd person assistance allowance (Segurança Social 2017b). From the beginning of my fieldwork (2013), the legislation regulating the SEE - *Subsidio de Educação Especial* (Special Education Aid) has deeply changed and the number of disabled children and young people entitled to this allowance had notably decreased (Instituto Nacional de Estatística 2016)⁵². The rejection of many subsidy requests resulted in dozens of administrative court judgments presented by parents and to a parliamentary question⁵³. This situation led the Portuguese Association for Specialized Support Care (*Associação Nacional de Empresas de Apoios Especializados*) to force the Social Security Institute to review the new measure for the allocation of the benefit (Viana 2016b), and eventually in May 2016 the Government intervention restored the criterion according to which long-term disabilities should be flagged by means of a medical certificate (Viana 2016a).

Living after compulsory school: housing and job options for adult with ASDs

So far, I have explored parents' advocacy on issues such as autism awareness and social inclusion and provided some parents' narratives about discriminatory beliefs and practices against their children with autism especially with regards to school access and inclusion. The school environment represents a focus of parents' advocacy because it is the place where social policies are supposed to implement capacity building interventions and strategies for inclusion. A student with a disability who is eligible for special education services is guaranteed to receive support until he or she obtains a diploma or turns 18 (in this later case, regardless of obtaining the diploma of any cycle or level of education). After compulsory school, the social security system is, then, supposed to help disabled students and their families by planning their transition to adulthood and by providing adult disability services, such as vocational training, sheltered employment, housing assistance, and day programs (Shattuck et al. 2012). The allocation of these services depends, however, on their availability and on public funding. Not surprisingly, leaving high school is a monumental step for people with autism and their families. Along the years, the FPDA have been promoted many conferences and public initiatives about life planning and employment for adults with ASDs⁵⁴. During our long conversations, Dr. Isabel

⁵² According to parents, this situation is mainly the result of a protocol signed in 2013 by the DGEstE and by the Social Security Institute, which assigned to school's headmasters the task of identifying the eligible students.

⁵³ The question was submitted by three political parties, the PS - *Partido Socialista*, BE - *Bloco de Esquerda*, and the PCP, *Partido Comunista Português*.

⁵⁴ For instance, in 2015 the FPDA organized a seminar "*Autismo e inclusão no trabalho*" about job inclusion; here the link of the event <http://fpda.pt/autismo-inclusao-trabalho-16-de-outubro-de-2015>.

Cottinelli Telmo, FPDA president, has emphasized that transition plans to adulthood have long been aborted by the lack of resources and by the “structural absence of State who abandons the young people of the country”. Likewise, parents blame the State to do not provide suitable supportive measures, depriving their young children of any future chance. Pedro, for instance, compares the forthcoming transition to adulthood of his son to a “desert, where it’s hard to don’t lose the coordinates”.

During adolescence young people experience physiological changes and relational challenges and face an increasingly complex social milieu. These challenging might be harder to manage for a teen with ASDs. The liminality of this life period refers not only to the delicate path towards adulthood but also to the precarious life conditions of adults with autism. Indeed, after reached the majority and finished the compulsory school, a person with autism might not find an alternative supportive social environment and could thus lose whatever opportunity to daily socialise with a group of peers. As argued by Rapp and Ginsburg (2010), when a child is diagnosed with a disability “kinship, caretaking, and the life course are reconfigured [and emerge] a new kinship imaginary” (idem:517). According to most of the parents, there exist few options available for individuals on the spectrum when it comes to future life scenarios. Families face the void of services, the lack of targeted-adult programs of intervention, and end up by keeping on fulfil the role of primary care providers. With the exception of people with a so-called high-functioning autism or Asperger syndrome, the most part of adults with autism still requires long-term care, as well as encouragement and moral support in pursuing an independent life.

Sometimes long before the end of high school, parents are already looking for the best programs and facilities targeted for young people with autism and are particularly worried about living arrangement. Some scholars have argued how adult people with autism were more likely to live under supervision compared to persons with emotional disturbances and learning disabilities (Anderson et al. 2014), while others investigated how different residential trends - such as living at home or in non-family settings - may have both positive and negative effect on both families and autistic adults’ quality of life (Krauss, Seltzer, and Jacobson 2005). With respect to my fieldwork, the majority of parents I encountered hope to be able to privately cover for health-care services and psychological support so that their children may keep living at home. For these parents, living in the same household facilitates the emotional stability of the family and is considered a way to prevent their teen and adult children from isolation and social

exclusion. On the contrary, other parents consider their children's full-time inclusion in the family context as a harmful solution insofar as it may limit the socialization to a family-based network and burden their own care responsibility. Since caring for an adult autistic individual will become a more difficult task once they get older, many parents envisage to enrol their adult children in part-time courses, social projects and activities held by supportive structures, such as adult day-care centres designed to provide support plans for adult disabled people. Only parents of children with severe symptoms and co-morbid conditions say to may be willing to pay a long-term care facility able to host and take care of their relatives, bringing out one of the most emotional issues of parenting of a child with a disability. In this regard, it is worth reminding that since the high degree of diversification of "autistic traits" produces manifold ways of being autistic, once again the so-called "autistic individuals" might actually require a range of very different services and treatments. Also, the heterogeneity of conditions grouped under the category of ASDs makes difficult to outline an evolution-model of autism in adulthood (Anderson, Liang, and Lord 2014; Orsmond et al. 2013), producing instead uncertainty. This composite nature of autism(s) determines thus different evolutions, challenges, and futures. As I have previously underlined, the majority of the activist parents I have encountered has children and teenager affected by a range of mild to severe symptoms of autism, meaning that some of them have problems with social communication and interaction, live with pervasive behavioural problems, use non-spoken communication, and have cognitive delay.

As I have briefly exposed in Chapter I, during the 19th and early 20th century, asylums were the main system of care for patients with severe mental disorders and intellectual disability. Psychiatric institutionalization represented a model of custodial care and treatment devoid of any long-term vision. The deinstitutionalization of psychiatric patients became a widespread alternative to the asylum as soon as its negative impacts on individuals in terms of isolation, social stigma and abuse started to be reported. As Chow and Priebe (2013) further underline

“besides the upcoming civil rights movement and the right to receive treatment in the least restrictive environment possible, advances in antipsychotic drugs and alternative care in community enabled the release of patients from mental hospitals. Moreover, the high cost of inpatient mental health care became an increasing financial burden for the developing welfare state” (idem:169-70).

Yet, the implementation and development of mental health community-based services in the country faced several obstacles (Chapter II) and still represents a challenge for the Portuguese mental health system, whose weaknesses are worsened by a dramatic underinvestment of resources and by the lack of integration with the general health and social care systems, including housing, welfare and employment services (Caldas de Almeida and Killaspy 2011:1).

Another of parents' concerns with regards to the transition towards adulthood is represented by sheltered employment, which refers to “a wide range of segregated vocational and non-vocational programs for individuals with disabilities, such as sheltered workshops, adult activity centers, work activity centers, and day treatment centers” (Kregel and Dean 2002:64). Accordingly to several scholars, social inclusion becomes a more dramatic issue to deal with during adulthood because of the further challenges involved in the job market and professional insertion (Barahona Corrêa and van der Gaag 2017; Murphy et al. 2016). As I have already mentioned at the beginning of this chapter, the APPDA provides residences housing and services for autistic adults who need full-time care assistance, a Centre of Occupational Activities (CAO) and skills training workshops. The aim of these services is to facilitate the inclusion of adult people with autism within the broader social context by helping them to improve their competencies. Despite the efforts, parents argue how in Portugal sheltered employment programs are almost insistent, especially for adult people affected with severe symptoms of autism and co-morbid conditions.

Forbidden words

Despite legislative and policy efforts, individuals with ASDs and intellectual disabilities continue to experience social inequalities and material disadvantages, such as poverty, isolation, and discrimination.

The Observatory for Disability and Human Rights (ODDH) explicitly addressed this issue during a 2016 two-day symposium in Lisbon entitled “The Disability Convention 10 Years Later: Research, Policy and Practice”⁵⁵ (12th and 13th December 2016), an event organized to commemorate the 10th anniversary of the Convention on the Rights of Persons with Disabilities

⁵⁵ “*A Convenção da Deficiência 10 anos depois: Investigação, Políticas e Práticas*”, program available at www.oddh.iscsp.ulisboa.pt/images/Mediateca/Not%C3%ADcias/PROGRAMA_-_SIMPÓSIO_10_ANOS_DA_CONVENÇÃO_DA_DEFICIÊNCIA_12-13_Dez._2016.pdf

(from now on CRPD)⁵⁶. The CRPD generally states that people with disabilities have the right to equality before the law, as well as the same access to rights as other people. During the opening session, the delegate of the United Nations Committee on the Rights of Persons with Disabilities who attended the event as keynote speaker formally declared that Portugal did not yet achieve the legal recognition of persons with disabilities nor ensure their rights to independence and individual autonomy (article 3). A particular concern was also expressed in relation to “legal capacity” right, which refers to a person’s ability “to exercise her legal rights and obligations on an equal basis with others and in all aspects of life” (article 12). In this regard, people with so-called cognitive delay or impairments do not demonstrate or enact agency in typical ways (Kittay and Carlson 2010:6–7) and may have difficulties in performing cognitive skills such as reasoning, reflection, judgement and deliberation, which are seen as necessary to live in society as full social and political subjects (Simplican 2015). Similarly, as some people with autism may show some cognitive impairments, their legal capacity may suffer some restrictions. Despite parents are aware that intellectual disability represents a “threat” and a challenge for their children to enjoy social and political rights, they criticise the way in which intellectual disability is “used” to create a barrier to their children’s full societal inclusion and to deny their equality of rights. While I will later explore the complex relationship between intellectual disability, disability rights and citizenship (Chapter VI), in what follows I report how parents, while being aware of their children’s difficulties with regards to self-sufficiency and autonomy, critically discuss about social policies’ topics such as guardianship, self-determination and legal capacity. As well illustrated by Pedro, for instance, early intervention therapies “have changed the idea that autism is forever [...] and that the autistic person could never change or evolve”. However, he is aware that beyond some improvements, an adult with severe autism and comorbid conditions will barely be an autonomous person. Furthermore, the idea of adult people with autism as individuals unable to survive without protection contributes, in my view, to the emergence of another discriminatory phenomenon, namely infantilization.

On more general terms, disability is often associated with words connoting childhood or referring to child-like features. Some of the parents who have adolescent children, for instance, have told me how friends or relatives occasionally refer to their sons with terms generally used for children, such as “little” and “cute”, as well as measure their cognitive ability using

⁵⁶ The Convention on the Rights of Persons with Disabilities was adopted on 13 December 2006 at the United Nations Headquarters in New York and was opened for signature on 30 March 2007. Portugal ratified it in 2009.

expressions like “it’s a three-year-old brain”⁵⁷. Children are usually the subjects of our conversations and we often assume that kids are unable to make their own decisions and unable to think for themselves. A child is someone who has to be cared, monitored, and protected by others. In this regard, the expression “adult disabled people are like children” presumes that they are incapable of caring for themselves and making their own decisions and for this reason as people in need of someone to act in a “parental” role. Infantilizing people with disabilities means to ignore their wishes, peculiarities, dignity, and self-esteem. With regards to autism infantilization, there are further considerations to discuss. The most part of descriptions and accounts about people with autism released by parents, charitable organisations, and popular media particularly focused on children. Both local and international support organisations show in their online homepages children with autism, as if the face of autism was always that of a child. Similarly, biomedical and social sciences’ researchers have restricted their descriptions of autism to child-referential investigations. My own fieldwork primarily focuses on parents who have children diagnosed with ASDs. Autism infantilization has been already discussed in a 2011 essay authored by three scholars (Stevenson, Harp, and Gernsbacher 2011), one of whom is an autistic self-advocate, who analysed the role played by parents, charitable organizations, the popular media, and the news industry in infantilizing autism. Their investigation found out how the characters depicted as autistic were children in 90% of fictional books and 68% of narrative films and television programs and that the news industry featured autistic children four times as often as they featured autistic adults in contemporary news articles.

On this topic, I would like to report an episode occurred once a national TV news report was posted on the *Os Amantes de Saturno* and greeted by some parents as a praiseworthy example of social inclusion. The video entitled “More than 30 children of Castelo Branco see the sea for the first time”⁵⁸ actually showed adolescents and adult people affected by different types of

⁵⁷ The tendency to infantilize adult people with autism is correlated also to intellectual disability. As a matter of fact, from birth to adulthood we grow up mentally, physically, emotionally, even spiritually, picking up new information and making new experiences from our surrounding environment. Part of this growth is learning social skills and developing cognitive abilities. According to developmental psychology there is a specific set of skills - intellectual, physical, practical, emotional, social - that almost every abled person learns according to different age rates. The concept of IQ, for instance, measures a person’s skills by comparing these latter with those of other people of the same age and allows psychologists to isolate people who supposedly show abilities under the average level of cognitive performance. As a result, when an adolescent or adult person with a cognitive disability is described as having a “mental age” of a child, she is understood as a person who does not act nor understand as it is socially expected.

⁵⁸ Sic TV channel, news video at <http://sicnoticias.sapo.pt/pais/2015-04-29-Mais-de-30-criancas-de-Castelo-Branco-viram-o-mar-pela-primeira-vez>, 29th April 2015.

disabilities enjoying their first day at beach. Zelia was particularly upset by the positive reactions that parents shared online on the topic and eventually addressed me privately with a message: “WHAT?! CHILDREN?!?! Why is this news? Why is this still happening in the 21st century? As long as parents agree with this [way to see adult people as children], why should we expect society to change?” I had a great deal of consideration for her outburst and tried to calm her down. This episode shows how infantilization still represents a common attitude towards people with mental disorders or intellectual disability, as well as how some parents fight for people to employ a language able to respect the dignity of adult people with disabilities. As she later explained me, she is no longer able to withstand people calling and treating autistic people as children regardless their age. Her reaction also shows her rejection to praise events considered exemplary just because related to people with disability:

“go to the beach or at the supermarket should be normal...so why is it still a utopia for disabled people? I already fight against a society that pushes us at the margins and tries to let parents give up on their fights...but those commentaries hurt because they are parents too! Those parents feel good about adult people treated like children but they should also have to understand that there are other parents who may want a different future”

Infantilization and the supposed inability of people with autism and disabilities to “fit” into adulthood may also led to disregard other aspects of their life, such as sexuality. Treating a person with a disability like a child may led, for instance, to do not acknowledge her sexual desires. This process of “de-sexualisation” may also led to treat her as genderless, as unisex toilets for disabled people show. The idea that disabled people have “certain desires, such as having sex” - said once Olga - “is hard to accept because we think it’s inappropriate, like we do think for a child”. As she argued, since all people deserve to have meaningful and loving relationships, society should assist disabled people in their sexuality’s needs. Furthermore, disabled people do not receive sex education like their peers do. Because of this, according to Pedro, people with autism do not know how to have safe sex or how to recognise and express their sexual desires and pleasure. In order to contribute to the exploration of these issues, several scholars have investigated the ways medical and social environment conceived disabled people’s sexuality and addressed their sexual needs (Earle 1999; Esmail et al. 2010; Mona 2003). Others have investigated the multifaceted relationship between abled people’s attitudes and perceptions towards sexuality of people with learning and intellectual disability (Cambridge and Mellan 2000; Cuskelly and Bryde 2004; Gilmore and Chambers 2010) and

explored intellectual disabled people's sexual knowledge and how to teach them sexual education (Galea et al. 2004; Gougeon 2009; McCabe and Schreck 1992; Schaafsma et al. 2015). In my view, the denial of disabled people's sexuality and sexual needs lie in their bodies' "troublesome" nature. In order to overcome the anxiety towards "different bodies" - not normative-reproductive-abled bodies - society silenced their sexuality and forced them to be "bodies who never grow". As Olga expressively argued, people with autism are thought as "little angels, asexual, as if their body was a dead zone in terms of desires". Also, Pedro argued how people with physical and intellectual disability are "forced to do not own their bodies in a lot of ways (...) such as [with regards to] their sexual life".

Similarly, masturbation represents for society's another taboo topic according to parents. In this regard, when I met for the second time Pedro - after 2 years from our first interview - his son Francisco was 14 years old. After having received some complaints from Francisco's teacher as he allegedly tried to touch girls' private parts, Pedro started to give him "some tips" on how and where to masturbate. As he further explains:

"I don't think about the possibility to hire a person [a sex worker] for this purpose...this is still a grey area, yet I know that is an issue already discussed on an unofficial basis by parents who have children in residential care (...) I mean sex, masturbation, the sexual desire in general...all this should be discussed openly and we as parents need some guidance on how to deal with the topic".

People with autism, as well as many people with disabilities, are denied their sexuality by the stigma that usually surrounds disability. In this sense, support and advocacy groups give to parents the chance to talk about their doubt and worried in a "protected" context where to question normative ideas of sexual desire.

Challenging an uncertain future

So far, I have explored parents' apprehensions with regards to long-term dependency, the lack of adequate social services for adult people with autism, as well as different forms of stigmatization suffered by adult people with autism. Here, I want to eventually describe parents' concern about their child's future. In particular, since people with autism have difficulties to attain independent living and self-care skills, many parents express their fear when it comes to their own death: "what will happen to my child when I'm gone?", "Who is going to take care

of him?” “Where and with whom he will live?” These questions brought more anguished worries to an already uncertain and precarious situation.

The idea of their autistic children’s abandonment, neglect or isolation represent for a parent the worst possible scenario. Also, long-term semi-institutionalized residential care facilities risk, for almost all the parents I interviewed, to increase people with autism’s social exclusion. At first, I thought that the feeling of discouragement and fear about one’s own death was obvious for elderly parents as Elisabete. This was not actually true. The absence or unavailability of family members - such as siblings - to take parents’ place after their death intensify parents’ fears about their child’s future. Elisabete has experienced State’s lack of commitment to finding concrete solutions for the social inclusion of adult people with autism. Indeed, her 42-year-old son Jaime is actually living inside one of the APPDA’s residential care facilities since he was 18. Because of his profound autistic symptoms and co-morbid conditions, and also because during the mid-70’s - when he was diagnosed - he did not receive appropriate therapies or treatments, he now needs 24/7 care assistance and supervision. With some regret, Elisabete has accepted that Jaime’s housing arrangement in a long-term setting represents the best solution possible. Yet, she is still concerned about the possibility that her son could not remain inside the residence once she will die because of the State’s denial to keep cover the costs. On one hand, for those people with ASD who need intensive care and constant supervision and whose parents or other relatives cannot longer taking care of them, the inclusion in long-term care facilities represents a social right and a way to enhance to the greatest extent possible their life. On the other hand, long-term and institutionalized residential care facilities never represent for parents a “desirable” choice.

Zelia, whose son has already 13 years old, addressed the local health authorities several times in order to know more about available services for adult people with disabilities:

“I’m a single parent and I’m already been forced to ask for a part-time job to be close to my son. I need more help! I need the State takes its responsibility and allows parents to have a two-day break, a chance to relax (...) there are moments of infinite fatigue, exhaustion, I wonder what would happen if I have a nervous breakdown, actually I had it once and I remember those [workers] at the Social Security Service looked up to the sky and didn’t say a word...then they said there are a lot of semi-public and private adult day-care centres that organize social or recreational activities, but now let me ask you...when my child will be 20 [years old] do you

think that playing, singing and drawing will still be a form of rehabilitation? This will help him to join society?”

Like Zelia, also Irene voiced her feelings of sadness, anger and disappointment when thinking about her child's uncertain future. For her social policies agenda keeps on disregard adult disabled people's life and well-being and she burst into tears while thinking that one day she may “fall into the temptation to abandon Osvaldo” inside a long-term care institution. At this regard, she eventually proposed me to join her and other activist parents to support a campaign called *Queremos uma política de vida independente contra a institucionalização* (We want a policy of independent life against the institutionalization) promoted by an independent movement of people with disabilities (*d)Eficientes Indignados*⁵⁹. The initiative was launched some days after the proposal of the then Portuguese Solidarity and Social Security Minister Mota Soares to employ European funds in order to build more institutions and residential homes for disabled people. The Minister announced his intention during the inauguration of a €1.2 millions residential home - called CerciPeniche, in the municipality of Peniche - destined to 24 people with disabilities. The group (*d)Eficientes Indignados* accused the Minister of disregarding the European guidelines regarding disability's politics⁶⁰ and disabled people's rights, speculating about the Minister's personal interests to facilitate building contractors. For Irene, politicians “don't understand what independent living means! But little by little, we will succeed to overturn this situation! Because there are too many institutions sponging off disabled people and living at the expenses of those who are institutionalized!”.

The creation of residential homes contributes to hide and “privatize” disability, increasing the social exclusion of people with disabilities and depriving them of the opportunity to live within society at large. Parent advocacy, in this case, aims at reverting any oppressive marginalization and seeks to influence social policies and practices to promote disabled people's inclusion (Ryan and Runswick-Cole 2009; Winter 2003). As I have mentioned, the admission in a long-life institutional residency represents an undesirable fate. Therefore, parents fight to subvert the precarious conditions under which their children are reaching adult life. These daily efforts of parents to balance their hopes and desires with the precariousness and uncertainty of their children's future deeply touched me. At the same time, I acknowledge their frustration and

⁵⁹ (*d)Eficientes Indignados* - webpage at www.facebook.com/dEficientes.Indignados/.

⁶⁰ At this respect, according to the European Expert Group on the Transition from Institutional to Community-Based Care, the EU Investment Policy Regulations include specific references to the commitment of European Union towards deinstitutionalization and so commit the EU funds only to community-based projects.

anger when dealing with public cost-cutting measures and inadequate services that inevitably contribute to turning health care assistance for adult autistic people in an additional social and economic burden on the public health budget.

So far, I argued that parents engage with disability rights movement and fight on their children's behalf in order to challenge disabled children's precarious process of reaching adulthood and to eventually overcome a perspective that sees family (in particular mothers) and care institutions as long-life vicarious subjects who substitute the self-determination of the autistic people. For these reasons, school inclusion, sheltered employment and social services for adult disabled people represent urgent social policies issues. By raising public awareness about disability issues, parents also want to confront public stigmatisation and prejudices and replace the impairment-based language through which autistic people are generally and roughly described and understood. A language that speaks about deficits, low functionality, unintelligible differences prevents any possible comprehension and respect of the Other.

Politicising day-by-day practices

As parents of a child with autism, mothers and fathers take on the responsibility to assure their child is receiving appropriate therapies and services and that her rights - formally recognized by legislation - are guaranteed within the broader social context. Parent advocacy is especially important when the subjects involved cannot self-advocate because of their young age or of cognitive, sensory, physical, or developmental challenges. The purpose of this section is to explore parents' individual experiences with their children with autism through the lens of their advocacy practices, especially by focusing on the collaborative and collective dimension of parent-to-parent support group; this latter is intended as both a tool and a space for parent to "take action" and to be part of a community. While the most part of the individuals I encountered was connected to one or more support and advocacy group or platform, some parents show a more individual way of advocating. It is important to stress indeed that as "autism" actually implies a cluster of autisms, also parents' experiences of living and caring for a child with autism are multiple and varied. Similarly, the practices parents engage in as advocates and the claims, demands and fights they make on behalf of their children vary over the time. My concern is to be able to really show both the differences and the commonalities of these parents. This represents for me a crucial issue that navigates throughout my thesis. Indeed, while describing my fieldwork and constructing my ethnography, I feel the tension between the necessity to portray the uniqueness of each parent's experience, namely parents' intragroup

heterogeneity, without neglecting the similarities and bonds that keep them together as a community and support their collective identification as parents of a child with autism.

On becoming an advocate

As I have tried to show in this chapter, parents' involvement as advocates on behalf of their child follows some particular steps. After their child received a diagnosis, parents get into a journey for educate themselves about ASDs and other possible comorbid conditions. Thanks to different resources of knowledge, such as health practitioners, scientific articles, biographies, fictional books, and also the Internet, they learn and share their own understanding of autism. During this phase, parents also seek for support and advocacy communities, which provide them with practical resources - such as how to access services, medical care, and supports for their children with autism - and psychological help, in order to cope and handle how means to parenting, living and caring for a child with a long-term pervasive neuro-developmental disorder. These communities give also parents the opportunity to share their child's clinical histories, their own worries and hopes, as well as the expertise they have acquired. Commonality and membership involvement allow parents to make friendship, which turns to be crucial for those who felt isolated from their social circle. Once a child finally reaches the schooling age, parents search for both therapeutic and educative supports and try to create a collaborative partnership with their child's teachers, as well as with her classmates and their parents. Under those circumstances, parents learn how to navigate the complex and time-consuming bureaucratic procedures of the institutions providing services and supports, how to enforce the legal obligations towards people with disabilities and through which legislative procedures it is possible to file a complaint for discrimination and breaches of human rights. All this journey fabricates parents' expertise about how to parent a child with autism and how to advocate on her behalf⁶¹. Finally, as I described in the last paragraphs, after compulsory school, families face challenges with respect to living arrangements or sheltered employment able to accommodate the needs of their adult child. In Portugal, the economic crisis and the cut in public funding translate into a severe reduction of state involvement in transition planning and services targeted for adult people with autism. At this regard, parents feel concerned for the lack of continuity of programs and services that can support and achieve social inclusion in

⁶¹ In my fieldwork, only few parents have children not affected by severe symptoms of autism and cognitive impairments. In this case, they tried to acquaint their children with self-advocacy skills so that they could understand their own needs, communicate them to teachers or classmates and ask for help to overcome some crisis or difficulties when at school.

adulthood. As a result, the transition to adulthood and the experience of moving from parental care to semi-institutionalized or community care are referred to as a time of uncertainty.

By listening to their stories, their individual experiences as well as participating with them in some events, I recognize how parental involvement and experiences in autism advocacy are multiple and varied, a conclusion reported also by other ethnographies or case studies that has focused on parents of children with autism (Rehm et al. 2013; Ryan and Runswick-Cole 2009; de Wolfe 2014; Wright and Taylor 2014). People describe their own approaches to and sense-making of activism in different ways, producing different narratives of it. For instance, some parents engage more actively in the public sphere while others prefer to be involved in a more private setting. Similarly, some of them talk openly about their child's strength and weaknesses while others may struggle to publicly share their own concerns. According to their own individual interests and expectations, parents are different kinds of advocates. For this reason, parent-led advocacy phenomenon comprise a multiple range of practices such as sharing information with other parents, fighting for an inclusive education, participating on online discussions, attending meetings, promoting petitions, monitoring the provision of services, debating with people in public space in order to negotiate and dispute the meaning of autism, as well as demanding recreational activities for children with special needs and community resources for adult people with autism (such as residential care placements and support programs). The approach to advocacy practices is very diversified, because these practices result from parents' own experience and degree of involvement, as well as from the specific traits and needs of their autistic child. Advocacy movement then favours a plurality of actions and shows different ways to think civic and political engagement.

The specificity of autism online advocacy and its (expected) impacts on local context

Further to the above considerations, the diversity of advocacy lies also in the manifold of places or locations where advocacy discourses and practices come to live. While the most part of offline mutual support and advocacy groups for parents are usually affiliated with autism institutional associations (such as the APPDA), online communities are characterised by more informal criteria of belonging and they mainly respond to thematic topics (ex. parents of autism, food and autism, autism in Portugal etc.). Both contexts are crucial for parents in order to demand health and education services, to advocate for their children's civil rights, as well as to raise awareness about autism. Likewise, both networks constitute a platform where knowledge, experiences, and practices are shared in a transversal way. Accordingly, my research demanded

interrogating parents about what they do, following and participating in their activities on social media platforms (Facebook groups), as well as in face-to-face events. My study on parent-led autism advocacy movement, thus, traversed both online/offline contexts, navigated both online and face-to-face fieldwork interactions. While exploring the broad content of parent advocacy in Portugal, my main interest was how parents engaged in social media and virtual groups in order to advocate on behalf of their children and which kind of impact their online activism has in the local context. Indeed, as I earlier clarified, even if digital ethnography does not involve the ethnographer travelling physically to a field site (Hine 2000:43; Kulavuz-Onal and Vásquez 2013), doing research online means to inhabit an ethnographic sensitive place (boyd and Ellison 2007; Parks 2011; Pink 2009) and to engage with issues that are “particularly relevant in relation to specific localities” (Postill and Pink 2012:123). The online communities I anthropologically investigated are *places* where activist parents deploy advocacy practices and discourses on behalf of their children, and perform their political and affective ties to the cause of autism and to the community itself (Downing et al. 2001). The use of social media is a trend that occurred with other contemporary forms of activism (Blood 2001; Dahlberg-Grundberg 2015; Gillett 2003; Marichal 2013). In order to explore this feature, I fabricated my fieldwork as a multi-sited ethnography (Marcus 1995), which led me also to take different and creative methodological choices. In order to avoid any misunderstanding, I define my work as a multi-sited ethnography not because I conduct my fieldwork in different field sites but because I investigated my topic - autism advocacy movement - through different social settings. Its multi-sitedness has to do, then, with the interconnectedness of the autism advocacy’s narratives, practices and features through different overlapping spaces and social contexts, and it cannot be disjointed with the more global context (Falzon 2016; Hine 2007).

The online support and advocacy group *Os Amantes de Saturno* on which I focused my analysis functions as a supportive community that helps parents to alleviate their doubts and concerns, to feel comforted by each other help, as well as to overcome the feelings of isolation and loneliness they usually said to experience. Parents engage in productive dialogues thanks to online discussion threads covering different topics addressing the daily difficulties parents encounter in caring for children with autism (from sleep issues and gastrointestinal problems to school placement and health services). Parents may share a post, write a comment, read a content, as well as produce a database of resources accessible anywhere online, 24/7 by other parents. Parents appreciate the opportunity to communicate with people going through similar experiences and having the same needs and concerns. By sharing their own stories, parents may

help other parents and ask for support and encouragement. This type of exchanges is critical for them in order to feel mutually supportive, to recognize their commonalities and create a sense of community, which is eventually lived also in offline contexts. Beyond coming across useful parenting information and hosting their advocacy's key demands, a large share of parents thus uses the network as a meeting place, instilling human value across their online relationships and creating thus a network of *actual* friends. Under those circumstances, the specificity of an online support and advocacy group seems to me lies in the greater ease with which it is possible to exchange information and knowledge, to express personal ideas, as well as to organise and spread advocacy initiatives and events. The online community has also a more active role in circumventing geographical boundaries, overcoming physical distance and reaching decentralized areas of the country. As a result, *Os Amantes de Saturno* puts also families in touch across the country, which reveals to be a crucial opportunity of those parents that do not have local parents-for-parents support group located close to their residential area. Finally, the virtual network may behave as an extension of other local support and advocacy groups but compared to these latter it is recognized by parents as an easier and safer place where to play criticism and to escape those hierarchical relations that could underpin more formal and institutional autism association. As a result, it follows more equal rules of relationship so that parents conceive their advocacy group as an "inter-pares" movement.

Os Amantes de Saturno also hosts and advertises initiatives and events which aim to gain visibility within the public realm. In doing so, parents want to sensitize society to be more permeable to the flow of knowledge and meanings generated by their collective mobilisations and able to acknowledge their demands and to be eventually involved in disability rights movement. Indeed, through their advocacy parents are publicly exposing their own intimacy and beliefs to demand a change in society, an issue I will develop in Chapter VI. Finally, to achieve their legitimacy as advocates, parents use the online platform to describe themselves as experts to address autism-related issues and to prove to be qualified to speak on behalf of their children and of other people who are discriminated by society because of their differences and vulnerabilities. *Os Amantes de Saturno* represents also a space to fabricate a counter-discursive public representation of autism - an issue I will later address in this paragraph - and it gives a parent the opportunity to unveil social stigma, to recognize, describe and contest it, to eventually turn it visible.

In broader terms, virtual social networks can thus be conceived as technologically mediated political spaces where parents are demanding visibility, constructing themselves as activists and organising social mobilisation. Online encounters, reciprocity, social exchanges as well as mutual support and legitimization of their expertise represent the materiality of parents' virtual sociality. Within the digital world thus parents produce and establish a field of experience and relationships, which shows, in my opinion, the importance of the collective nature of these online groups as a multiplier of knowledge, social practices and human relations. In line with these considerations, I acknowledge parents' online advocacy as a technologically mediated tool of agency. Through the online platform, indeed, parents perform their practices and discourses of social engagement, which is oriented both towards the future, namely it imagines alternative life opportunities for disabled people, and toward the present, as it has the capacity to articulate parents' knowledge, experience and expectations within the contingencies of the moment (Emirbayer and Mische 1998:963).

Advocacy and the political transformation of self and intimacy

Through our social interactions, we speak and are heard by others in multiple processes of self-disclosure and learning. In doing this, we mediate our personal relationships and the construction of our own subjectivity. The experiences and the expertise acquired all along our life reshape, indeed, our identity, change the way we think and move us into the world. Following this idea, social interactions have a central place in the process of self-transformation and in our becoming individuals. In her introduction to the special issue "Intimacy and embodiment", Maclaren (2014) argues how intimacy must be understood as conditioned by our embodiment and as a process of significant others becoming a part of our embodiment.

As I earlier underlined, parents react to their children's diagnosis of ASDs in different ways, by remodelling their habits, expectations, and future desires. "You need a lot of imagination and improvisation to be a parent of an autistic child" - said a lot of parents to me. Also, they creatively perform their expertise on the autism spectrum with health professionals, teachers, other parents, relatives and strangers. Parents argue that the "autism" label has a tremendous impact on the reorganisation of their lives. They employ the biomedical category to refer to their children, to their advocacy work - "autism advocates", and also to their experience of parenting and caring for a person with autism - "autism parents". Their daily activities, the care choices they make on behalf of their children with autism, the relationships they maintain with other parents, health professionals and educators, the ways in which they conceive and relate

to their child according to a continuous process of attention to and learning from their peculiar traits, all of this transforms a parent into an “autism parent”. However, as de Wolfe (2014) clarifies in her ethnography about a New York City support group for parents of children diagnosed with autism, while parents acknowledge autism

“as a term to index, an identity to reference, or a label with which to situate themselves, they explain that it can never fully describe the complexities of their lives (...) it is not the autism label that defines their lives, rather it is the daily activities each of them dedicate to caring for their children that define their lives and, in so doing, define autism for each of them” (idem:5).

Similarly, I acknowledge how in my own fieldwork the multiple experiences of parenting and advocating for autism have a different influence on parents’ life and understanding of autism. Given those points, in what follow, I want to theoretically frame how to conceive and understand the transformation of parents’ intimacy and the construction of their subjectivity once autism has entered in their life. As shown earlier in this chapter, parents have adapted their daily life routine and their parenting expectations to the needs of their child and adjusted their familiar setting and their social relationships (with friends and their close social environment) to their new condition as a family living with and caring for a child with autism. My point is that also their own subjectivity, their own self, has intimately changed. Life experiences and the socio-cultural, political and historical forces that traversed the social context within which an individual lives have a profound effect on her personhood and are acted upon in view of the transformation of the self. If on a first insight, those considerations tempted me to conceive parent’s subjectivity as expressively “political” because of civic engagement and political mobilisation. Later, I recognized how the sense of the *politicality* of parents’ subjectivity does not merely lie in their advocacy discourses and practices.

Complying with this latter intention, I was looking for a notion of “political subjectivity” that acknowledges the political nature of subjectivity as embedded in every aspect of life and rooted in the broader socio-cultural and historical context. This nuance of the notion is brilliantly provided by Sadeq Rahimi (2015) in his book *Meaning, Madness and Political Subjectivity*. Throughout his analysis of three case studies of people living with schizophrenia in Turkey, the author considers the ways in which private experience is shaped by the collective structure of political and social power. According to him:

“the notion of political subjectivity dramatically widens the scope of ‘politicality’ to understand the subject itself as a political event. In other words, here the subject is conceived of as political in its very subjectivity - both in the sense that it engages in an ongoing act of subjugating and conjugating the world into meaningful patterns and in the sense that the subject is continuously subjugated or conjugated by the local meaning system. Politicality, in this sense, is not an added aspect of the subject, but indeed the mode of being of the subject, that is, precisely what the subject *is*” (idem:8).

Rahimi embraces and strengthens the idea that “political” does not merely refer to what people do, but instead to something that is intertwined with the sense of subjectivity that makes us human beings. Accordingly, insofar as the human subject is political in her deepest sense - namely in her ways to be human - the politicality of the parents I encountered and interviewed in my own research is not limited to their struggles or resistances but covers all aspects of their subjectivity. Indeed, it is impossible to conceive the subject in any fashion divorced or abstracted from the struggles she undertakes within the realm of social power and the context of meanings in which subjectivity comes to exist. Subjectivity is indeed also fundamentally and intimately context-dependent. Furthermore, as Rahimi further underlined, the political can be located “within the apparatus of meaning making” (idem:9), which is the process through which we as human beings make sense of and are made sense by the Other.

Equally, I recognise subjectivity as intimately political because the subject stands within and along a continuous and extended process of transformation of her own (transient) identity. The thinking of the Italian philosopher and politician Gramsci and in particular his notion of “microphysics” of social transformation is another significant insight that allows me to think about individual agency within the tissue of collective advocacy. It is worth stating beforehand that Gramsci’s thinking about the formation of subjectivity is framed by Italian political authoritarianism and workers council movement of the early 20th century and that his specific concern was to understand culture as thinking in action, that is, as a dialectical process of production and transformation of the self within a field of historical forces. Arrested by the Italian Fascist regime in 1926 and imprisoned until near his death in 1937, Gramsci suffered physical and psychological tortures and experienced the privations and sufferings of the prison system. During these years of painful isolation, he wrote touching letters - lately collected as *Letters from prison* (2011 [1971]) - concerning his own condition and experiences that resulted in extraordinarily penetrating intellectual and political insights. The collection of letters reveals

indeed a man that struggled - as well as his other companions (most of whom also political prisoners) - with the fear of illness and death and that bravely tried to nurture his emotional bonds and relationships despite being separated from his sons, family and friends. For what concerns my purpose, I would like to report Gramsci's insight about the role of the political, cultural and social forces, namely the power to transform subjectivities. As he argued, behind the constitution of the subject lies a process of "molecular transformation of subjectivity" (Gramsci 2011 [1971]:258–59), which happens along one's everyday social interactions.

The transformation of the person is called molecular because the body is the minimal unit of experience, representing thus the ultimate event to take into account in order to grasp the processes of this transformation. Inspired by Gramsci's thinking, I often reminded me during the fieldwork the necessity to observe, participate and interrogate the ordinary dimension of parents' experience in living, caring and advocating for a child with autism. Indeed, it is by investigating people's practices in a way as close as possible to their experience - through the key ethnographic method of participant observation - that anthropology is able to grasp and reveal the transformation of the self. Also, in their narratives, parents speak about their own transformations after their child receiving a psychiatric diagnosis and presented themselves as different persons since then. The auto-representation of the self as "autism parents" reveals the parents' need to give sense and order to this process of renovation. Eventually, I am also indebted to Gramsci's thinking insofar as his focus on the "molecular" dimension of the impact that socio-cultural, historical and political forces have on the individual emphasises the phenomenological question of body government, which refers to the intimate and bodily dimension of power and to the dialectic bond between the State and the individual. At this regard, Righi (2011) designated Gramsci within those Italian thinkers who have contributed to think and construct the concept of biopolitics. In particular, according to the author, the biopolitical in Gramsci is to be intended as "the site of the dialectic between oppression and spaces of affirmation" (idem:170), which is the individual self. In my case study, parents' subjectivity embodied this dialectical position when, for instance, they act on their child's behalf and negotiate, criticise and regulate the governance practices that social and health policies prescribed for their children as non-normative bodies and subjectivities.

Advocacy as a tool to affect society

To further understand parental advocacy, I will finally explore another aspect of their role as autism advocates. Especially during informal conversations, parents promoted themselves as active citizens who campaign for their children rights and perform a form of political mobilisation able to *change* society.

In their study about mothers of children on the autism spectrum who act as advocates independently or collectively (as inside advocacy groups), Sara Ryan and Katherine Runswick-Cole (2009) argued how some of them adopt an “enhanced advocacy role” that can be conceived as “precursor to a broader, external activism in which the focus shifts to campaigning for change outside the family” (idem:50). In this regard, Searle-Chatterjee (1999) considers advocates as activists when they meet one of the following criteria, (1) they describe themselves as such, (2) they take a leadership role in relevant organisations, or (3) they simply spend considerable amounts of time and energy on the cause. Despite she does not address disability activism, some of the parents I encountered fit with her criteria while some others did not expressively describe themselves as activist nor have necessarily taken up a leadership role. Furthermore, there are also parents who - despite consider themselves and their child as members of a socially excluded group subject to discrimination - refuse to claim their identity as “parents of a disabled child” and to adhere to a medicalized and not socially grounded understanding of disability (Goodley 2001; Oliver 2013). Following Ryan and Runswick-Cole’s cited work (2009), then, I acknowledge how advocacy and activism may be experienced “on a continuum” rather than activities following strict definition criteria. In a later work (2010), the authors also suggest how:

“If social mores once dictated that family members with disabilities be hidden from view and stories about them silenced, [now] this cultural script is being revised on a daily basis, creating a sea change felt across multiple locations, from the intimacy of kinship to the public worlds of educational policy, scientific research, and popular media. (...) the ‘public intimacy’ now claimed by members of families and kinship groups with people with disabilities has become highly visible in other parts of the globe in recent years” (Rapp and Ginsburg 2010: 517).

As I have shown through different ethnographic vignettes in this chapter, parents use support and advocacy groups to put pressure on political representatives to address disability issue, social justice and inclusion. As advocates, parents become intermediate subjects between their

own children with autism and both educational and health institutions entitled to negotiate their demands and accommodate their needs. Indeed, also because of the inadequacy of institutional support and the failure of social integration policies, in Portugal the family still remains the main responsible for implementing people with autism's emotional and material environment. Moreover, government austerity measures and the reduction of welfare support constraint parents to dedicate themselves to a full-time role of caregivers, contributing to strengthening a parental guardianship strategy. While the responsibility to protect and ensure disabled people's rights is believed to primarily belong to the them, parents ask for a change in society so that civic activism can finally become an instrument carried out day by day by all citizens. In my fieldwork, advocacy provides opportunities for parents not only to express their own demands but also to fight for a more inclusive society. Through more formal advocacy events (like petitions, campaigns, marches, participation in conferences and speeches at school), as well as more *impromptu* daily practices (negotiating their children's presence in public places, facilitating their children's interactions, speak with people encountered by chance in the public space), parents aim to raise public awareness of autism and sensitize others about social justice, equality and marginalized people in society. For these reasons, the decisions they make for their children, the demands they are claiming for them, as well as the advocacy practices they engage in, constitute a consistent part of their life not merely as advocates of a child with autism but also as active citizens.

Parents' commitment is socially powerful because it crosses the supposed boundaries between online and offline practices of advocacy. The examples I reported throughout the chapter, indeed, attempted to prove how online advocacy aims to have repercussions in face-to-face contexts. Online petitions, for example, are used as an assisting tool in advocacy campaigns not only because they increase autism's media outreach but also because they are linked to a broader campaigning for social change. Actually, sign an online petition in itself is not like "taking action" and advocacy campaigns could probably achieve a success without the aid of an online petition, but they surely gain media attention as quickly as they did because of the public support they gained through gathered signatures. In this regard, some media critics called online campaigns worthless and an example of "armchair activism" "keyboard activism", "clicktivism" or even "feel-good slackivism" a combination of the words activism and slacker (Butler 2011:15). Shulman's (2009) article *The Case Against Mass E-mails* is considered the most articulated critique to "clicktivism". In this article, he defined the online campaigns of the EPA-Environmental Protection Agency about mercury rulemaking as low-quality and less

effective mobilizations that crowded out traditional public efforts to the detriment of the Democratic process. He finally argued that emergent forms of online activism may bring to a limited political impact due to the lack of true and continuous involvement and to a “disengagement of the citizenry”, weakening the rulemaking process as a whole (idem:46-7).

Paying particular attention to Shulman’s article, Karpf (2010) challenged his claims and argued that interpretations of and attitudes towards online campaigns may have to be revisited when it comes to their internal constitution and their modes of working. As a result, the distinction between “offline” advocacy and online activism may lie in a *difference-of-degree* rather than a *difference-in-kind* (idem:9). Online forms of activism that emerged within the digital era have created, indeed, some changes and challenges to traditional views and meanings of activism (Butler 2011). Scholars addressed the problem of managing visibility within social media activism and investigated the role of affect in building and maintaining dissident publics over longer time frames (McCosker 2015). Literature in this field has also suggested that the Internet has changed the political basis of activism by stimulating the emergence of a new kind of activist (Blood 2001). For instance, Marichal (2013) argued how politically oriented Facebook groups allow actors to construct desired “possible (political) selves” through the formation of idealized political identities and discussed the implications of these virtual groups for the future of digital citizenship. The Internet has thus greatly increased the effectiveness of activist groups in many ways. In this regard, some authors have demonstrated how new communication technologies provide political groups and movements with new ways of mobilization and organization (Galis and Neumayer 2016), as well as how social media enable activist groups to have a more effective and powerful impact on collective action (Dahlberg-Grundberg 2015).

Following these latter arguments, autism virtual advocacy has the potential to achieve its aims in the broader social context, as well as to raise public awareness of autism towards people who are not personally concerned with an autistic individual. As an example, it revealed to be particularly powerful in questioning public representations of ASDs. I refer in particular to parents’ public disapproval of a misleading vision of autism as a familiar tragedy, as well as of the common use of terms such as autism/autistic to indicate someone who is shy or suffering of social anxiety, or simply has some communications issues. In this respect, parents often blamed the media to have contributed to the spread of a narrow and bi-dimensional image of autism through the figure of the “weird talented” or “tragically misfit” autistic child, which

transmit both the idea of the autistic person as a socially unadapted individual⁶². This statement reveals, thus, parents' intention to encourage society to rethink its way to understand and depict autistic people's non-normative ways to express the self and their sociality. As socially non-compliant bodies and subjectivities, autistic people may eventually bring - as I will explore more in detail in Chapter VI - new perspectives to think human sociality. It is worth recalling, for now, how psychiatric categories - such as autism - has a contingent historical nature, meaning that they are subject to psychiatry's epistemological changes and temporary settings of power as a discipline that identifies, describes, classifies (and thus constructs) behaviours as pathological conditions. Following those authors who have conceptualized psychiatry knowledge as an institution of social control (Conrad 1992; Foucault 1965; Szasz 1974, 1994), Moncrieff (2010) defines psychiatric diagnosis as "political device" insofar as it fulfils the function of social control by identifying and containing disturbed behaviour in order to enforce certain rules of conduct while "dressing up normative judgements about (this) behaviour as medical facts" (idem:371). At the same time, however, a psychiatric category is not an external armour that acts upon the human being but instead a malleable configuration in which individuals could acting upon (Hacking 2006). According to this dialectical view, if psychiatric constructs can be negotiated by both diagnosed individuals and their social environment, parents are entitled to work through their interactions with the broader society for the replacement of a disabling and discriminatory language that defines their children as socially disabled or unfunctional.

Another mainstream misleading idea about people with autism considers them as dependent individuals, incapable of expressing their own personality and of achieving self-independence. This ambiguous representation materializes itself - as I shown earlier in the chapter - in the infantilization of adult people with autism and in the common use of expressions of pity and sorrow addressed to parents in the public space. Parents' accounts about how "autism" is lived and addressed in the public space are, therefore, crucial to investigate and reveal the practices of marginalisation (often silent and not visible), the moral judgments about disability, and the

⁶² Actually, the idea of autism as a disturbance of social relationship resulted from a new notion of the "social" brought by psychology's advancement (Danziger 1990; Evans 2017; Rose 1985, 1990). In particular, Hollin (2014) has shown how modern conceptualization of autism as a social disorder became dependent upon a re-articulation of "the social" - identified by Greenwood (2004) within the 1980s psychology - that meant that the object of social cognition is taken to be the immediate interpersonal environment while the processes that govern it are the intrapersonal cognitive mechanisms (Hollin 2014:109). In the field of autism studies, this new understanding of the social led to the use of cognitive examinations and tests that by allegedly revealing socially abnormal behaviours "discover" a "hidden mass of socially pathological persons (...) whose differences were previously seen as non-pathological, unimportant, and/or simply went unnoticed" (idem:110).

ways through which society refuses to question its own discriminatory practices. In this process, parents aim at changing the (temporary) established knowledge about ASDs as a social and biomedical construction, confirming the “crucial role” of autism advocacy groups “in the development and understanding of autism” (Hollin 2014:109). From my fieldwork experience, support and advocacy groups gather epistemic communities that (re)produce and question medical authority and social politics, as well as negotiate and criticize public representation of autism in the broader social space. In this sense, autism has become an advocacy disorder, contributing to dismantle a mainstream view of autism as a tragedy, a trauma, a dismay, all words still commonly associated with having a child on the spectrum.

Parents’ social engagement with autism advocacy can be thought as a way to reconfigure their subjectivities as activists and as a form of “public intimacy” exposure. Their “advocate self” is then acted within the public space, showing their own citizenship’s values and meanings and their efforts to sensitise society at large. As well expressed by Pedro, advocacy is a “civilisation” matter insofar as parents are creating

“a new generation of citizens much more tolerant of *difference* and willing to support an equal society (...) all those people who care about a more tolerant society should embrace parents’ interests and demands. When there are not shared purposes, society cannot make progress and cannot become a healthy society”.

Chapter V

Affectivity and engagement

For a critical reading of gendered practices of care and advocacy

As these chapters reported, care and advocacy represent the two main areas in which parents of children with autism are actively involved. The reading and analysis of what parents do in both childcare and advocacy practices allow me to consider the complexity of the experience of living with, taking care of and fighting for a person with autism today. I come into play in my writing with who, as a mother or a father, is daily feeling the pleasures but also the fatigue and difficulties of caring a child with autism and advocate for her. Both childcare and advocacy represent indeed joyful and fulfilling tasks but also emotional burdens, and both have consequences on parents' subjectivities. Moreover, given that autism is a long-life condition, parents feel care and advocacy as long-term activities as well, and this often increases the degree of vulnerability that they feel about their own and their children's future. In what follows, I will explore the gendered practices of care and emphasise parents' use of affectivity and love as a political tool to reach society. This chapter contains 2 sections. In the first section, I will illustrate fathers' involvement in childcare and their call for its recognition. This portrays is partial and limited because of fieldwork's temporal constraints and the restricted number of fathers I encountered. In the second section, I will address mothers' affective discourses and practices of mothering a child on the spectrum as a political apparatus and focus on their role as advocates. As I often underlined, the most part of my fieldwork interlocutors were mothers. For this reason, the ethnographic vignettes of the last section will particularly emphasize their role as leading figures of the autism advocacy movement in Portugal.

Silenced Fatherhood - Beyond absence and underestimation

As I previously illustrated, people diagnosed with autism often need long-term care and commitment. As all children, they need to be raised, nurtured and taught about everyday world but unlike the majority of adult people, they may still need to be fed, bathed, and taken care. Care work represents thus a compound of fundamental tasks for parents of people with autism and this daily labour involves the most intimate spaces of their everyday lives and bodies, homes and family context. Virtually in every society care shapes people's everyday lives and relationships. At this regard, understandings and experiences of care, as well as caring relations

and practices, inform and are shaped by the wider socio-economic and political context in which people live.

The edited volume *Critical approaches to care* edited by Rogers and Weller (2012) shares the argument that “all human societies require the provision of love and care, that interdependency is the ‘condition’ of human beings and that love and care cannot be understood without recognition of the ‘gendered order of caring’” (idem:4). This expression - gendered order of caring - was originally developed by Kathleen Lynch and Maureen Lyons (2008) in order to underline the influences of gender relations in relation to the experience, social organisation and political understanding of care. Despite mothers represent the main subjects of my fieldwork and even if I had not the opportunity to deepen fathers’ experiences of care and parenting because of my fieldwork’s temporal constraints, in this first section of the chapter I wish to give my circumscribed account about men’s caring practices, understood - following Miller (2011) - as “men’s description of meeting the needs of a new and growing baby through hands-on practices, activities and emotional thinking, commitment and responsibilities” (idem:5). In this way, my aim is to contribute to a growing field of critical studies about men’s parenting, care work and involvement in their children’s lives (Gray and Anderson 2012; Hobson 2004; Pattnaik 2013; Ranson 2015; Wall, Aboim, and Cunha 2010; Wall, Aboim, and Marinho 2007). While recognizing the gender bias of care work, I will advance the idea that care work as a gendered practice need to be interrogated, as besides overburdening women and devaluing their labour, has also a role in unrecognizing fathers and silencing their presence, contributing to a trivialization of both men and women’s personal *choices* as caregivers. Indeed, care work as a set of bodily and emotional practices can be learned and both men and women can become competent. By gathering men’s considerations about what it means to be fathers, what they are doing as caregivers and in which ways they engage with their children, I acknowledge the bodily and emotional capacities they bring to fathering practices and caregiving. Indeed, fathers’ experience of this “embodied caregiving” has important consequences for them as they become competent in its practices and “in the process of acquiring this competence, they change, in ways that are deeply significant for their relationships with their children and their partners, and, some would argue, for the wider world” (Ranson 2015:1).

Men breaking the silence

Among the parents that regularly share their experiences, post links and articles and comment other parents' posts and questions in the *Os Amantes de Saturno* online Facebook group, Diogo is one of the most active. During our face-to-face conversation, I had the opportunity to ask about his role as a father in caring and advocating for his child Luis. Diogo considered himself a single parent, as he divorced from his first wife and his new partner does not take part in the education and care of Luis. As he often pointed out, his regular and extensive presence on the group online page results not just from his role as administrator but from his commitment to giving space to fathers' voice, which is not particularly present in the group. To underline his role as a father in his son's daily life, he used to post photos of his child Luis playing football with him or going for vacations as well as write about Luis' evolutions and experiences at school. To directly face the topic about fathers' involvement within the group, he once shared a post entitled "A mother - autism on the other side of the door"⁶³ originally published in *Poder dos Pais* (Parents' power), a Brazilian blog from Evellyn, a mother of 3 daughters, who from 2013 to 2016 (when she eventually took a break from the blog) shared her thoughts with Portuguese-speaking parents of children and adolescents in the autism spectrum. Although the blog's intention is to address both mothers and fathers, Evellyn's posts often refer to mothers' experiences and point of view. In the "About me" section she described herself as a full-time "super mother with all her flaws!" who acquired her "superpowers" when her daughter Stella, to whom the blog is dedicated, has been diagnosed with autism. The post shared by Diogo related a typical day of a woman fictionally named Márcia waiting "on the other side of the door" where her son Pedro does therapy. In Evellyn's words, Márcia starts thinking about the uncertain future of his son and revealing her concerns, her daily struggles, her constant commitment to her child, her personal choices and her contrasting emotions like the desire to surrender and the will to fight despite everything. The author ends the story with a committed and empathic "You are Márcia, I'm Márcia" as to ask for an identification of other mothers with her description. In his comment below the link, Diogo wondered "Does anyone is feeling like Márcia here in our group? I think this name is neither female nor male because I also see myself as Márcia!"

Some women admitted the importance of their male partners' presence in their children life, endorsing the often-underestimated father's role as a caregiver while others complained about

⁶³ See here the entry blog <https://poderdospais.wordpress.com/2013/07/11/a-mae-o-autismo-do-outro-lado-da-porta/>

their husbands' absence or marginal role, pointing Diogo as an "exceptional case". Following the online opposite comments about father's role, Diogo reiterated his personal commitment to support other men in stepping up the role as fathers of children with autism and the need to turn autism advocacy movement more aware of the father-child relationship. In this way, he hopes to sensitise broader society about the importance of fathers' involvement in a child's growth and development. The idea of the father's role - he continued - should gradually change from seeing the father as the one who merely provides financial and instrumental goods to that of a more committed family member who undertakes increasing responsibility in his children's educational and care needs. He agreed with me in seeing my difficulty of encounter activist and caregiver fathers during my fieldwork because of this marginal role and supported my will to focus on the engagement of fathers to create greater opportunities for them to speak up.

Ivo too is particularly critical to what he called an "extreme exposition" of mothers, which ends up compelling them to that "shaming feeling" of being responsible for almost all the aspect of their children's life. Ivo's wife, for example, is likewise engaged in Alex's education and care so that they both share as parents an equal primary role as caregivers.

"It's an extremely sexist thing! And I abominate it...the Moms of Autism! Mums of everything! Okay, I realize that in disability, mothers have been more visible but there are two aspects (to be considered) ...one is that the mother faces the disability in a different way and this is described in much literature, there is a completely different view of the mother and the father, because the child is born of the mother and this relationship is considered more complex, isn't? But what is more penalizing the female sex than the male it is that the mother gets the idea "it was (because of) me" and from this comes the attempt, and I know many mothers that do that, of giving everything to alleviate this feeling "I'll give it all, I'll do everything to reverse this situation, because I have a feeling here of guilt!"

As I already mentioned, the most part of the parents I encountered during my fieldwork were women. They represented the primary caregivers of children with autism and the more engaged figures in advocacy activities. This more presence of mothers depends on the gendered role of care but also by the higher number of female-headed single-parent families I encountered. Among my 19 long-term interlocutors, 10 are single-parents, one is widow while 9 are divorced, only 1 of the divorced parents was a man, and only 2 (a man and a woman) remarried or have a new partner. As some studies revealed, there has been observed a higher rate of divorce among

parents of children with developmental disabilities (Namkung et al. 2015) as well as with an ASD (Hartley et al. 2010) compared to parents of children without disabilities. As I remarked this data during my conversation with him, Ivo outlined how despite some quite high divorce rates in families with a disabled member “there are still a lot of husbands and partners beyond these mothers of autism” and then annoyingly said: “mothers are not alone, but they like to show they are alone!” In his view, this auto-representation of mothers as the ones that “work the most and spent most of their time with these kids” contributes to the perpetuation and proliferation of those theories that burden mothers for their children’s failures and progresses:

“In my case, it was me who discovered my son’s autism, my wife did not even know about it, I started to search the net because of his behaviour...you know I have this mania that I understand medicine (...) I was almost sure [that was ASDs] and I told the paediatrician to do some tests, later I went to a child psychiatrist and only then my son was eventually diagnosed with autism at 2 years almost 3 years old! But I suspected about it when he was still 18 months! This is inadmissible, paediatricians need more training and the development area of study is very mistreated in paediatrics, it’s a shame! I see a child on the street and I know to diagnose her while a paediatrician doesn’t know (...) and then there is a another thing...because when the doctor said “he’s going to be a Mozart, don’t worry, this is all reversible!” my wife and I came home all happy! But it was the worst thing they told me in my life! They don’t have to say this! (...) When *Vencer Autismo* said that autism does have a cure then you have desperate parents who will never mourn, I have mourned for a long time, I have two children and I do my best for my autistic child and even if he develops zero for me he is equal to the other one; if I don’t do like this, I’ll never be happy!”

Ivo eventually shared with me how he learned through his autistic child to become “more emotional”, that is to educate himself to express in more visible ways her feelings and emotions in public. For his son Alex, the touch is a crucial communicational tool and bodily contact became something important to the development of an emotional relationship with him. Ivo’s words represent what Ranson (2015) called fathers’ “experience of the bodily dimension of caring” (idem:3) in the extent to which men’s body and touch aspire to be viewed as kind and caring “just as tradition has allowed this understanding of women’s bodies” (Hamington 2011:275).

The case of Pedro is peculiar as he is taking care of his son as a single parent and primary caregiver only recently. According to Pedro, autism has a brutal pressure in his relationship

with Francisco's mother and it represented one of the motives of a worsening of their relationship. Indeed, when Pedro eventually divorced from his wife in 2001, Francisco was in custody of her mother who kept living in Lisbon until she decided to go to Mozambique in 2009 without Pedro's approval. When I first met him in 2013, Francisco - at the time with 12 years old - was still living with his mother in Mozambique. During these years of long distance relationship, Pedro was in contact with his son especially through Skype and he often registered their conversations as well as Francisco's new reactions and his heightened emotional arousal due to his adolescent's mood swings. He suffered a lot because of this separation and felt guilt for his absence as a father: "I have to tell you that for me now it is very distressing, because before this situation I was always there...in the waiting room of doctor's office, at therapies, at school, at the hospital, as you might imagine I gained hundreds of hours of it!"

When in April 2016 I eventually met again Pedro, he was already living with his son from almost 2 years, since after 5 years being in Mozambique with his mother, he fought in court to have Francisco's full custody. In this regard, he expressed how for a lot of people this may seem strange "because the father is stereotyped, he is kind of considered incapable of caring for his child". In his view, the role of fathers is misrepresented and paternity itself is not valued within broader society:

"I will tell you if a father asks for paternity leave people's comments are "eh eh he just wants vacations" and on the contrary if a mother doesn't ask for work leave the reaction is "oh look she isn't careful, she doesn't care, she is not doing well for her child"...there is a very strong construction and pressure in both cases (...) this thing that only mothers know how to do this (care for) has to do with the idea that since they are closer at a biological level they then have a special connection with the children"

Fathers' absence in care work and parenting literature

Children with disabilities often require more extensive family involvement and greater paternal support than other children. The most part of the literature I have analysed on parenting a child with autism focuses particularly on mothers' experiences and perceptions. For instance, scholars emphasized how mothers of children with autism experience higher levels of stress, anxiety, depression and psychological distress (Dale et al. 2006; Estes et al. 2009; Ingersoll, Meyer, and Becker 2011; Phetrasuwan and Shandor Miles 2009) as well as general poorer health and wellbeing (Safe et al. 2012) compared to mothers of children with other disabilities

or typically-developing children. Other studies found how mothers raising a child with autism are more likely to challenge parenting self-efficacy, that is the feeling of competence in the parental role as it is associated with well-being, agency, and positive parenting outcomes (Kuhn and Carter 2006) and that mothering another child with a disability (in addition to the child with ASD) result in higher levels of depressive symptoms and anxiety and lower family adaptability and cohesion (Orsmond, Lin, and Seltzer 2007).

Some studies also approached autism parenting challenges within the whole family context, finding how autism severity and low adaptive functioning is a significant factor affecting parental reactions to parenting (Poslawsky et al. 2014) and generally associated with increased parenting stress (Hall and Graff 2010, 2011). Others analyses focused on the emotional consequences of coping and dealing with autistic child's challenging behaviours and on parents' adaptive behavioural strategies, as well as on the stigmatized judgements from strangers that cause extreme stress levels and negatively affect family well-being (Ludlow et al. 2012; Osborne and Reed 2010; Zhou and Yi 2014). Eventually, comparative studies focusing on the differences and similarities between fathers and mothers coping with child's autism argued that both mothers and fathers of children with ASD show higher levels of parenting stress and psychological distress (Davis and Carter 2008) as well as a higher prevalence of both depression and anxiety (Almansour et al. 2013) than parents of typically developing children. However, autistic children's behavioural challenges and delays in social relatedness resulted in elevated parent-child relationship problems and distress for mothers who showed higher depressive symptoms and parental stress compared to fathers (Dabrowska and Pisula 2010) as well as to other parents of typically developing children (Oelofsen and Richardson 2006).

A recent review, surveying articles on parents' experiences of caring for a child with ASDs, reports how mothers are over-represented subjects and suggests that this "gender imbalance" is due to mothers' role and experiences as primary caregivers (DePape and Lindsay 2015:580). Indeed, despite fathers increasingly adopting this role, mothers do remain more likely to be primary carers. Some studies explored the role of father as secondary or marginal career in family with an autistic child, highlighting how father's role as a caregiver is harder to fulfil than mothers as child care work is considered a female priority leading to higher rates of employed fathers in couples with an autistic child and to a less involvement of fathers in their child's daily care routine, an activity that involved female partners much more extensively (Gray 2003:635; Pelchat, Lefebvre, and Perreault 2003). While these studies also reported a gendered tension arising from mothers' perception of not receiving enough spousal support, other scholars report

partners growing closer as a result of jointly caring for their child (Hock, Timm, and Ramisch 2012; Markoulakis et al. 2012).

Fathers' caregiving is generally considered in the context of the gendered division of household labour, or of broader gender differences in parenting. Beyond the idea that mothers are always primary caregivers, this underestimated focus and gap in the literature about fathers' role and emotional consequences in caring for a child with autism is due also to the undiscussed gender differences in coping with a child with a disability. Indeed, the literature I have related above on parenting a child with autism has focused on inherent gender-based differences in coping to explain the differential impact of autism on men and women's life and has largely reported that mothers are more vulnerable than fathers to stressful events such as diagnosis, coping and strangers' judgements in public as well as more exposed to psychological suffering because of gendered form to face with emotional events. Fathers are indeed frequently described as acting in a "practical and rational way" rather than mothers and as paying less attention to emotional aspects when faced with stressful situations.

Gender seems thus to be implicit and taken for granted factor, and for this reason, it needs to be critically discussed. Indeed, much of this mentioned literature has equated gender with sex and failed to focus on the embodied experiences of parenting and caring role. In other words, the relationship between gender, parenting and coping that are grounded in the gender roles assigned to men and women in our culture need to be contextualised in fathers and mothers' unique life and care work's choices. On one hand, mothers and fathers occupied distinct roles in the family as result of the influence of their social and cultural environment, so that the different experiences of fatherhood and motherhood should be explained by gendered embodiment and social and moral norms attached to gendered parenting. On the other hand, some fathers might not see their own concerns as sufficiently important or legitimate to raise because of the moral demands and discourse around fathers' primary role as breadwinner and thus negotiate a dilemmatic situation of their apparent acceptance of being less involved (Ives 2014:1015). In his qualitative analysis on the role of gender and coping among parents of children with autism, Gray (2003) found that different meanings of disability among mothers and fathers could give rise to various strategies of coping with their child. The author also claimed that aging is a good term for analysing parents' coping strategies changing over time (2006), while highlighting how "whether the issue in relation to coping is gender, age or any other social distinction, the priority should be on examining the ways in which experience

affects coping rather than attributing coping behaviours to supposedly inherent qualities” (Gray 2003:633)

Researches exploring parents’ experiences of having children with autism have often underrepresented fathers, resulting in a significant gap in the literature covering paternal role and care work. However, some recent studies focused on non-resident biological fathers of disabled children and explored their supportiveness, relationship, and nursing practice, reporting fathers’ discourses and significant challenges about fathering and how their emotional interactions significantly improve the quality of father-youth relationships (Shandra, Hogan, and Spearin 2008), while others explored fathers’ positive aspects and perceptions of their parenting a child with Asperger, highlighting in particular the funny moments or emotional events like receiving an hug (O’ Halloran, Sweeney, and Doody 2013). Burrell et al. (2017) have also recently investigated men’s experiences of fathering children with ASD, indicating how fathers described their experiences as a path towards acceptance and how they saw themselves as advocates fighting obstructive services to access appropriate care. For the most part, all these studies claim how even as “secondary carers” fathers represent an important support within the parenting dyad and their experiences and choices have an impact on their father-child relationship.

In search of recognition: fathers claiming for fathering

The focus of literature on mothers caring a child with autism - as implied in my review in the previous paragraph - has often left out of attention the narratives of fathers about their experiences and perceptions when they are engaged in their children’s lives. Despite I was aware of the necessity to take into consideration their different concerns and experiences, I should point out how eventually in my ethnography - despite my efforts to encounter them - fathers represent a minority of interlocutors. I succeed having long-term communications with just four fathers and only two of them, Pedro and Diogo, “became” primary caregivers because of their marital status. These fathers are not exempted from stress and emotional difficulties in parenting a child with autism and they are engaged with their children as fathers and not just as “one-half” of the parenting dyad. Their fathering practices and their role, however, are considered in a certain way as uncommon or at least unusual compared to mothers.

Emanuele, for example, confesses that he sometimes gets undue praise for doing what actually his ex-wife is expected to do for their daughter Isabella, such as accompany her daughter to the

hairdresser or help her choose feminine clothes. Similarly, he feels to be also underestimated by some friends that - he suspects - think about him as an occasional babysitter and not as a father who is parenting Isabella. The examples reported by Emanuele elucidate, in my view, how men that attempt to perform more involved care roles feel frustrated by others' lack of recognition. Moreover, the fact that he shared parental responsibilities and that this elicits laudatory reactions implicitly reveals how fathers' caring role remains a relatively infrequent situation. Likewise, mothers' reactions to Diogo's post about the feminization of parenting role, for example, should be critically analysed to be beneficial for gender equity and supportive to men's role as caring fathers. The "exceptionality" attributed to these fathers' states, in other words, how broader society is still inadvertently reinforcing gender norms and that men and women are judged to be so subjectively different regarding care work that parenting is considered extraordinary when it comes to a man. These gender expectations show how people can perpetuate discriminatory effects even without intending to.

As Ivo once pointed out speaking about Alex's diagnosis, when he and his wife were both in the examining room he noticed how the paediatrician addressed the questions about their son's behaviours to his wife as if he weren't even there. Ivo considered himself as more knowledgeable about autism than his wife and he made some efforts to be recognised and heard by the doctor even if his wife "allowed" him to reply to doctors' questions on her behalf. In most of the narratives about autism diagnosis, fathers usually "accompanied" mothers to doctor's appointments and despite their demand for attention they felt like "out of place". As he defended, "fathers should be more estimated (...) they bring a different perspective on how children stay at home, how they react to therapies, they can give a hand also to comprehend autism in a different way".

Similarly, Pedro outlined that when society fails to value fathers as caregivers, it consequently does not allow men to have an equal chance to care for children as well as women to have an equal chance to stay at work. At the same time, he is aware how caring a child with autism is unthinkable regardless a critical interpretation of the gender roles in care work. Pedro accepts in a certain degree his exceptionality insofar as he is a single parent with full custody of his son Francisco. While on one hand he is favourable for the recognition of fathers as involved carers and "emancipated men" who do not rely their masculinity on being breadwinner of the family, on the other hand he is aware that statistics still show that - unless stay-at-home fathers or single fathers - women are still the primary caregivers of children and still do the most part of home

chores. Indeed, while recognising these fathers' engagement and presence in their autistic children's lives, I found that in general fathers are not nearly as present as mothers.

Indeed, when I interrogated mothers about their partners' role with regards to child caring and autism activism, the most part of them argued how fathers were more likely to pick kids up from school or therapies rather than to attend autism-related events or to participate in conferences or petitions, confirming social expectations about gendered parenting involvement. In the most part of the families, mothers miss a male engaged figure but justify father's marginal or absent role alluding to the presence of a non-residential father in case of a divorced couple or in general to a "natural" attitude of mothers for caring. For instance, Rute explained to me that since her son Leonardo was diagnosed she has undergone "solitary struggles". This eventually led to divorce, underlying how she feels that mothers, as a rule, are more present and more involved than fathers, and how fathers who take on a leading role represent just "few exceptions". Bruna shares with Rute this narrative about "solitary struggling" as she divorced from his ex-husband when their son João was almost 5 years old:

"I've been struggled alone, without the support of my children's father who on the contrary has created many troubles as he never accepted the diagnosis or that his son was treated differently in special education classes (...) he has always been inflexible about that, which makes any conversation impossible. He argues that João should be treated like any other child, without any special attentiveness to learning how to live in the world as he is".

As in Helena's case, which I briefly described in the previous chapter, also Bruna thinks that his ex-husband shows an Asperger profile and that he has never been officially diagnosed. Indeed, according to her João's father has always opposed to their son diagnosis also because he does not want to recognise his own autistic condition. For this reason and because of her will to safeguard her son relationship with his father, Bruna silenced her own difficulties and struggles as a mother caring and raising alone his (now) teenage son with autism. Beatriz, who is also a single mother, justifies mothers' more involvement with a metaphor illuminating cultural gendered representation about feminine and masculine roles in traditional families: "No doubt that mothers speak more with their hearts than fathers...I'm not saying that fathers are "emotionally dyslexic", I think it has more to do with nature or genetics. Mothers are more lion-like and fathers are falcon-like".

Also, coupled mothers share similar ideas about their role as natural carers. For instance, Raquel - who is remarried and has a 14 years old son Fernando - explains the prevalent number of activist mothers compared to fathers “because culturally this role as caretaker and this zeal for the children rights has been in mothers’ hand”. When I have the chance to further this topic with her as a single mother during an online chat conversation, she wrote how since there are many single-parent families with children with disabilities, mothers usually became the primary caregivers also because they usually keep the custody of their child, but then she further added:

“perhaps it’s also because of resilience...the ability of resilience it’s more typical in women...I don’t know, in my case it’s almost 4 years that the biological father of my son doesn’t meet his son and my [actual] partner, the stepfather of my son, is a man who supports us...immensely...but in a role that is, without a doubt, marginal”.

Like Barbara, who stressed mothers’ resilience in surviving to both physical and mental strain because of their partners’ less involvement in child care and raising, also Violeta reinforced the stereotype about mothers supposed natural attitude to fight for their children’s rights and wellbeing and innate ability to don’t surrender. Moreover, while applauded his husband’s ability to establish a relationship with his son despite his initial difficulties to accept his child’s long-life condition, she admitted seeking help from her husband “only in exceptional cases”. For instance, she laid claim to be “the one who deals with care and education matters” related to their son Filipe insofar for example she is the only one who negotiates with doctors a treatment decision on her son’s behalf or when it comes to improving Filipe’s socialization by organizing different opportunities of encounter with classmates or neighbours’ children. For this reason, she achieved family and friends’ acclaim for being, unlike her husband, the one who “takes the initiative in the family”. Among all the mothers that I had the chance to deepen this topic, only Laura and Luisa seem to have constructed an equal relationship with their partners with regards to care work as they affirm to equally share both care work and educational matters. They represent, together with Ivo and his wife, couples who espouse egalitarian family norms and share decisions around caretaking responsibilities. Luisa and his husband, parents of Igor who has Asperger, have other 3 children that also share responsibility for care work and Igor’s well-being:

“here at home both his father, me and his three brothers fight for him (Igor) to be as happy as possible. We all have important roles and we assumed that we had a difficult fight in front of us

and that it was important to raise our heads and go to the fight together and do everything for him”

Starting from these ethnographic excerpts, I can argue how mothers and fathers’ conceptions could reflect but also challenge parenting stereotypes. Insofar as people maintain gendered expectations about “a very involved mother”, fathers’ engagements in similar “involved” parenting practices - such as care work or worrying - is usually identified as “mothering” as well as their own actions are judged as “exceptional” or “really a lot for a father”. What I think was crucial in my ethnography regarding fathering practices is that men’s involvement in their autistic children’s lives is equally judgmental and evaluative than mothers’ involvement in both care and advocacy (a topic I will discuss in the next section of this chapter). Gender bias is then multifaceted, operating on both institutional (i.e. doctor-parents or teacher-parents’ relationships) and interpersonal levels so that for me it was extremely important to meet those fathers and ask them about their particular experiences and familiar situation. Ivo’s words illuminate his will to critically look at our own ingrained attitudes that view men’s breadwinner role nothing more than a privilege and women’s gatekeeping as a natural role.

The prevalence of mothers as primary caregivers - which reflect the gender division of labour grounded in the socio-political and economic division of work - will still nurture the stereotyped idea that men are incapable of providing those necessities - like care, concern and understanding - and that should leave parenting to mothers. However, as Ivo’s words claim, divorce does not always or necessarily result in absent or marginalized fathers. Both the figures of the female carer and of the male breadwinner represent gendered identities grounded in the cultural, economic and political conditions that produce and sustain the (gendered) division of labour market. At the same time, gender identities and social roles are largely products of cultural definitions of masculinity and femininity. A critical re-examination of gender roles will expand thus the possibility of challenging gendered practices of care.

Challenging gendered practices of care

Care is generally understood as the work of looking after the physical, psychological, emotional and developmental needs of other persons. It has been described thence as a polysemous concept insofar as in different languages it acquires the dual meaning of “to care for somebody” and “to care about somebody”. This twofold meaning captures the dialectics between care as a compound of activities and services on the one hand and as a manifold of social relations,

emotions, and affects on the other. Moreover, care embodies different cultural, ethical and normative notions about who needs care and who should care. Indeed, care is associated with responsibilities and needs, duties and expectations and these may change over time. The rights and obligations of care change over time with regards to the changing normative expectations of giving and receiving care during the different phases of one's life as well as because of the introduction of (new) different theories about human wellbeing or because of each national health care policies, reorganizations and medical services.

Medical anthropology enquired the domains of care within the different settings of health institutions (Mol 2008; Mol, Moser, and Pols 2010), care's local and global implications (Tsing 2000), the variety of human experiences around social suffering (Kleinman, Das, and Lock 1997) as well as the affective and political commitment to the well-being and care of and about others (Wilkinson and Kleinman 2016). Further investigations about care work and care relationships have also contributed to deepening our understanding of citizenship, justice, equality (Nussbaum 2006) and especially gender (Duffy 2005, 2011; Lynch and Lyons 2008). At this regard, the work *Critical Approaches to care* (Rogers and Weller 2012) contributes to the debate surrounding a feminist "ethics of care", a body of literature developed in the second half of the 20th century by feminist scholars (Gilligan 1982; Ruddick 1989; Tronto 1994) that shaped a critical view of established ways of thinking about gender by showing how caring labour is socially engendered to women. Moreover, as a social and emotional practice, care entails the capacity to make, shape, and be made by social bonds and relationships. Taking into account this element, several anthropology scholars that explored care at the intersection of work, kinship and life-course (Alber and Drotbohm 2015) discussing their mutual interdependence and constituency and highlighting how "care is a relevant and timely tool for examining the multiple dimensions of the distribution of gendered and generation-specific care" (idem:1). By studying the intersections of gender, race, class and the labour market inequalities, Mignon Duffy (2005) argued that in most part of societies a gendered division of labour has constrained women to perform care work as unpaid family work reinforcing unequal work conditions. In a more recent work (2011), she further explored how

"feminists scholars have understood the gendered division of labor that assigns care of home and family to women to be one of the linchpins of systematic gender inequality (...) (sine) women's responsibility for unpaid work in the home disadvantages them in the labor market,

both through periodic or long-term absences and through the burden of the second shift that wage-earning women still bear in the home” (idem:2)

Additionally, the settings in which care is performed often determine if this latter is qualified as work or as a duty:

“Is it the quality of an activity that allows it to be labelled as “work,” or is it rather the institutional and social framework in which it is performed? Does “care work” refer to the fact that a certain type of activity is delegated to another person who is paid for this activity? In some contexts, or institutional settings, such as kindergartens or nursing homes, care is perceived as professional and monetarized work. In other contexts, the same activities, such as spending time with a child and caring for it, are interpreted as an expression of parental responsibility and not necessarily as work (Alber and Drotbohm 2015:4).

Challenging the assumed gendered role of parental care does not mean to hide the fact that care work as a parenting duty is de facto regulated and influenced by gender bias. Indeed, the ethnographic vignettes I reported in the previous paragraphs show how childcare is immersed in and embedded with taken-for-granted assumptions about fathers and mothers’ roles as caregivers. The point at stake here is that narratives and practices of care inevitably *show* how gender is incorporated and performed. But they also reveal men and women’s critical awareness about the moral (and moralizing) connotations of the gendered expected duties and attitudes as parents (Duffy 2011; Rogers and Weller 2012). Therefore, I think crucial to observe and caught care practices and narratives within the dialectic time-space of daily life where gendered expected roles are actively negotiated and challenged by each parent’s efforts and determination to be acknowledged as a caregiver.

Despite gender did not represent a guide issue of my fieldwork’s planning nor the main key to the reading and interpretation of parents’ practices, fathers and mothers’ narratives addressed gender as a discrete interpretative element of their parenting practices especially when speaking about caring a child with autism. The ethnographic excerpts and observations I related in the previous paragraphs offer indeed some insights into the manifold gendered reality of care work and represent an attempt to grasp the variety of meanings and facets of care itself. More specifically, as I mentioned before, I bring into focus here parents’ narratives about paternal care work to give my humble contribution on the topic as well as do justice to those fathers I

had the chance to encounter and to their will to be contemplated for their care work and for this latter to be understood as a sensible aspect of their role as fathers. Indeed, the questioning of fathering practices, as well as men's decoupling from fatherhood, is often underpinned by the assumption that men do not necessarily assume the responsibilities of fatherhood and contribute to the phenomenon of solo-mothers caregivers in the household. However, men's emphasis on their emotional involvement in caring challenges this cultural cliché and shifts the focus on both policy discourse and laws that for long have defined fathers' responsibilities as largely directed toward cash rather than care (Hobson 2004:2-4).

Care as a creative place to dismantle male gendered subjectification

From the stories that fathers related with regards to their role as caregivers, I attempted to identify some aspects that deserve further consideration: a quest for fathers' recognition as caring subjects, the role of intimate bodily proximity in care work, fatherly love in child care narratives, and fathers' call for a greater involvement of fathers in caring for their children with autism.

The first issue is more directly related to the gendered assumptions about care work. Be they single parents - such as Pedro - divorced - as Emanuele - or with a partner - such as Diogo and Ivo, fathers are quite aware that the time they are supposed to devote to childcare and their duties as caregivers derive by already existing family and society's gendered norms. By acknowledging how the social perception of their role as fathers depends on a gendered economy of obligations towards children and family, they are trying to challenge it by exposing their own practices of care to be recognised as competent caregivers. In this sense, they are all questioning the "exceptionality" of their active participation in their child's care by "normalizing" this involvement. Spending time with their child and caring for her should be, in their view, an expected expression of their parental responsibility and affective involvement with their child. In my fieldwork, Pedro - who is single father and full-time caregiver of Francisco - and Diogo - whose new partner does not share equal responsibility for her step-son care - are more easily recognized as primary caregivers by family and friends than those fathers who have a female partner be a wife in the case of Ivo or an ex-wife in the case of Emanuele. In this latter case, the role of carer is more difficult to negotiate because mothers are usually widely entitled as primary caregivers so that both health professionals and friends struggled to recognize them as carers or invalidate their efforts to be acknowledged as active partners and involved fathers. To argue that this difference simply lies in the fact that Pedro and Diogo are

“going against the grain” because inasmuch as men they do a much greater amount of care work than is usually the case, results in a too narrow interpretation that could not but assume and thus reify the exceptionality discourse about caring involvement by fathers. While acknowledging the need of considering gender as a political lens when debating about care work and childcare fathers’ words and practices that I directly observed during fieldwork taught me how gender need also to be interrogated exactly when it is implicitly taken for granted with regards to care labour’s allocation of competence and skills. Fathers have confidence in their abilities, by caring they feel closer with their children and experience new ways of attachment that comes with care knowledge, and some of them truly aspire for an equal relationship with their female partners.

The second issue I identified in fathers’ narratives as caregivers - the role of body’s intimacy and proximity in child-father care relationship - relates to bodies’ boundaries on one hand and to kinship bonds on the other hand. I think, indeed, that both these aspects informed us about who and how one can (is allowed to) give care. On one hand, kinship - understood as a form of social belonging - should be “actively chosen, made, or maintained” and care practices contribute to its “making and maintaining” (Alber and Drotbohm 2015:2). On the other hand, beyond reproducing and confirming kinship relations, care also fabricates an intimate relatedness since as a labour inherently relational it involves bodily relationships. Both care and kinship are thus tangled with bodily intimacy, which - together with gender - shapes, regulates (allows or avoids) and governs both care practices and intimacy.

My thinking about fathers’ bodily proximity and intimacy in care work is in debt with Gillian Ranson’s (2015) recent work about fathers’ caregiving as embodied practice and lived experience and with her review of those authors who within the body of scholarship on gender have brought brilliant considerations to the topic of fatherhood and embodiment. In her introduction (idem:5-7), Ranson addresses the issue of men’s body perceptions in care work by recalling Andrea Doucet’s leading works on fathering, caring and embodiment (Doucet 2006, 2013), Connell’s work on masculinities and embodiment (Connell 2005) as well as Lupton’s concept of inter-embodiment, which captures the relational dimension of embodiment and the phenomenological experience of bodies as intertwined (Lupton 2012). The reading of these authors quoted by Ranson gave me the opportunity to deepen this issue and sharpen my critical thinking about the topic. Doucet’s two-decade-long ethnographic research on fathers’ care work contributes to making the embodied character of caregiving visible. According to the author,

embodiment *matters* in fathering practices as men emphasized the ‘masculine and physical’ quality of their caregiving - such as being outdoors, playing, and doing sports with their children - drawing “on a notion of masculine embodiment as strong, physical and muscle-bound” (Doucet 2006:711) and describing the uneasiness they experienced with the public displays of physical affection as this could be misconstrued:

“they feel that they have to initially watch their footing because there can be something disturbing about their presence as compared to mothers (...) the need to move cautiously because of ‘moral’ judgments, or suspicions about the social fit between male embodiment and other embodied subjects” (idem:712)

In my fieldwork, Emanuele has particularly expressed the uneasiness of his male body proximity while thinking of when his daughter will enter adolescence, that is when the bodily involvement of his caring may be problematic. Likewise, the proximity that care produces (Chapter III) reveals to be generally problematic for all those parents whose children face adolescence, puberty changes, and sexuality. As some authors advocated, the absence of fathers’ bodies in care studies is due do a narrow picture of their bodies that recalls a dominant understanding of masculinity as (supposedly) characterized by heterosexuality, hardness, roughness and aggression (Connell 2005; Gabb 2012). For this reason, men’s body proximity that occurs in the everyday practices of father-child intimacy is generally perceived as dangerous:

“Paradoxically, while physical and emotional closeness is being encouraged at the social level, as part of healthy fatherhood, the *innocence* of publicly displayed relationships between men and children (fathers and offspring) remains a source of cultural apprehension” (Gabb 2012:646).

This dangerousness of male body is - according to Connell (2005) - the consequence of a patriarchal vision of masculinity that contributes to silence the multiple identities of men, their position as gendered subjects and the complexity of their masculinity(ies) performance. In order to eventually dismantle these patriarchal forms of masculinity, men should envision and undergone a re-embodiment, that is a search for feeling, using, and showing male bodies in radically altered ways and care work represents - as she specifically pointed out - one fecund terrain in which this re-shaping could take place:

“Re-embodiment is involved, for instance, in changing the division of labour in early child care. As well as the institutional changes required, this has an important bodily dimension. Baby work is very tactile, from getting the milk in, to wiping the shit up, to rocking a small person to sleep. To engage with this experience is to develop capacities of male bodies other than those developed in war, sport or industrial labour. It is also to experience other pleasures” (idem:233).

The invisibility of the body - and especially of the male embodiment - in care studies represents thus a critical missing link for our understandings of gender differences in care work. Indeed, there always exist, as Doucet (2013) argued, an “ontological inseparability of body-social linkages and care-giving relations between carers and the cared-for” (idem:284). She calls, then, for a rethinking of the bodily quality of care by recognizing that this latter involves “fluctuating embodied entanglements - mind, muscle, flesh, breasts, lungs, hormones, hugs, physical play, arms, hands, face, neck, touching, holding on, letting go - and emotions of unbridled joy and unexpected grief” (idem:300). As Ranson suggested, Doucet’ thinking draws on Lupton’s work on “inter-embodiment” (Ranson 2015:7), the intertwined quality of bodies, that parents as carers experience for instance in their daily childcare work. Since infant embodiment and intimacy have been mainly studied in relation to the maternal body (Lupton 2012:46), Lupton called for more research not only on fathers’ ways of thinking about their own bodies and intimacy with their children but also on how they negotiate the emotional content engendered by the caring daily practices they are engaged with.

This last suggestion resonates with a further issue I identified in fathers’ narrative, namely love. By remembering my conversations with them, it now becomes clear to me how for them being a “good father” entails not only providing materially for the upkeep and the education of their children, but also providing immaterial care, such as guidance, love, and understanding. Their stories reveal their choices to devote their time to their children’s needs and to enrich their parental role with affective values. Fathers’ commitment is indeed strongly entangled with the rhetoric of unconditional love, a narrative often attributed only to mothers, whose descriptions about their affective attachment to a child is taken for granted and rarely questioned by others. This enduring sense of commitment to care a close kin is conceived and defined as a qualitatively different kind of work, namely a “labour of love” (Read 2007). Beyond affective bonds, care as a labour of love involves yet competencies, skills, knowledge, and precise routines. And Ivo, Pedro, Diogo and Emanuele represent in my view fathers who are trying to be recognized as able to hold and perform this care expertise. Providing care thus confirms and

reinforces the relatedness of parenthood and in this sense, it fulfils fathers' will to express their paternal love and dedication. In the case of disability, care - both as a parental duty and a labour of love - could be associated with the management, monitoring and surveillance of the intimacy of a person's life. A person with autism could indeed need extensive care and be dependent on her caregivers in most of the daily activities. Of course, as I have often underlined in the thesis, autism represents and articulates a manifold of different symptoms and characteristics and for this reason, it could not be considered an immutable identity, but a condition that generates a range of unique needs for every individual.

To address the fourth topic emerged from my interlocutors' narratives, namely their call for a greater involvement of fathers in caring for their children with autism, I would like to recall two considerations that I already stressed about the relationship between parenthood and autism. Firstly, at the beginning of this chapter, I reported how there has been observed a higher rate of divorce among parents of children with developmental disabilities and autism compared to parents of children without disabilities. This first remark prompted me to acknowledge also fathers' emphasis about the underestimated issue of the presence of single-fathers as well as of fathers as primary caregivers of autistic children. Similarly, since care work for disabled people is often construed as the "female private, and informal counterpart to productive public work" (Alber and Drotbohm 2015:3), fathers call both for the recognition of their role as caregivers and for the promotion of fathers' childcare responsibility. Secondly, as I mentioned in Chapter IV with regards to parents' insecurity about future, autism as a chronic condition can interrupt cultural and social norms with regards to kinship expectations of caretaking, disenchanting care perspectives on life course. Indeed, as people with autism could need long-term care, care role change in the life course is overturned. The transition from youth to adulthood implies the duty and the right to also provide and not just receive care. For this reason, a gradual attribution of changing care duties often marks this stage of life. Becoming adults, we all experience this new role of caregiver and of overseeing those in need, usually the older generation of our parents or grandparents who may be in need of assistance and care. In this sense, care connects individuals within and across generations and contributes to the construction of some expectations regarding who is eligible to provide and receive care. Fathers, as well as mothers, are also worried about the long-term care of their autistic children and about their future as independent and autonomous citizens.

In this section, I reported few case studies about fathers' practices and discourses of care that despite their limitations aim to acknowledge fathers' call for being recognized as caregivers and demonstrate the need to critically revise the gendered assumptions about fathers as "unable" to care or lacking "aptitude for" childcare. Moreover, my will was to show how fathers rely on their affectivity and emotions as part of their fathering experiences in a world considered as feminine and mostly inhabited by women and mothers. Regarding care, fathers shown a "caring moral orientation", which is more often acquired by and thus attributed to women, since they still represent the ones who usually do most of the caring. This focus on fathers' care work is particularly relevant, as care studies mostly have explored mother-child relationship as the main significant space where care and affective commitment to other are "naturally" intertwined. The "gendering of the welfare state" has, indeed, so much focused on care and motherhood that "feminist researchers did not see men, masculinities and fatherhood as part of the gendering project. Rather, men in mainstream welfare state research were viewed as gender-neutral citizens who happened to be men" (Hobson 2004:8). The questioning of fathering practices, as well as men's decoupling from fatherhood, is often underpinned by the assumption that men do not necessarily assume the responsibilities of fatherhood and contribute to the phenomenon of solo-mothers caregivers in the household. However, men's emphasis on their emotional involvement in caring challenges this cultural cliché and shifts the focus on both policy discourse and laws that for long have defined fathers' responsibilities as largely directed toward cash rather than care (idem:2-4). Despite care is fully recognised as an embodied aspect of motherhood, I have also pointed out how different scholars have already emphasised the consequences of gendered social roles on men (Hanlon 2012; Ranson 2015; Wall et al. 2010, 2007) and their experiences as gendered subjects (Connell 2005; Hamington 2011; Hobson 2004). By doing this, men are contesting traditional ideas of fatherhood and reimagining new practices of being a father that mirrors the changing perceptions of fathers as caregivers.

Heroic motherhood - Beyond sacrifice and empowerment

In this following section, I will address mothers' affective discourses and practices of mothering and advocating for a child on the spectrum as a political apparatus. I will argue that mothers actively employ and interpret their skills in childcare and their affective commitment in advocacy to validate themselves as leading figures within advocacy movement. As I will show, mothers politically use the assumed "feminine" emotions linked to motherhood - such as instinct, unconditional love, resilience, self-denial - to substantiate, guide and explain their own

commitment for social change. To comprehend their affectivity as a political capital, I will look at emotions according to Spinoza's concept of *affectus*, as this perspective acknowledges the capacity of emotions to increase people's capacity to act and to engage with the world. By considering affects as political motives, my aim is to critically understand autism advocacy as a meaningful form of political involvement of women in public space, showing the value of special mothering and maternal love as political experiences. Specifically, I will suggest how the intensive and tireless dedication to the needs of a child with autism as well as a strong commitment to advocate on her behalf do not necessarily produce and instill a diminished sense of self in a woman - who eventually is uniquely appointed to live and perform her role as a mother. Rather, they represent powerful *loci* (and experiences) where a woman can act her own script of mothering and being a citizen engaged for social change. While these latter considerations are in debt to feminist studies on motherhood, I owed the importance of considering mothers' lived experiences from that anthropological tradition that endorsed day-to-day life as the *par excellence* place where the self and its cultural and social structures are embodied (Csordas 1990, 1994). Also, my ethnographic attentiveness for the idiosyncratic nature of mothering practices is indebted to Bourdieu's notion of habitus as the place where subject's practices are continuously performed (Bourdieu 1977). Similarly, I gave particular relevance to the "ordinary" ways in which mothers' activism is performed because it is in everyday practices that people's subjectivity is continuously transforming itself and where the political content of these practices became visible. Indeed, as I already articulated, the constitution of the subject as political lies in a process of "molecular transformation of subjectivity" (Gramsci 2011 [1971]:258–59) that happens exactly during and within one's everyday interactions.

From bad to special mothering: how to escape from mother blaming?

Over the course of my fieldwork, I assumed mothers as expert interlocutors and knowing subjects. Besides interviews and informal conversations, I often had the opportunity to participate in some of their daily life's activities associated with their child's autism. The lexicon of affectivity and parental bonds as well as "special mothering" skills - namely specific competencies acquired in mothering a child with special needs - represented the framing arguments employed by mothers to explain and claim for their involvement in both autism care and activism. They especially used unconditional love and full-time dedication as positive topics to support and fortify their position as experts and advocates, challenging the long-term blaming they suffered in public opinion (Caplan 1998).

Indeed, although bad or poor parenting is now no longer believed at the origin of the ASD, the allocation of a properly personal dimension of guilt for their child's condition has not completely disappeared. Instead, it has been subtly replaced by the responsibility for the child's therapeutic improvement and progress. In other words, parents' (but especially mothers') blame has simply shifted from the aetiology sphere to the therapeutic one, so that "mother blaming" rather than disappearing adopted subtler shapes:

"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, locating and tirelessly attacking the threat of autistic symptoms through purchase of the right therapies; avoiding "toxins" in the diet, environment, and medicines; and accepting that autistic behavior is wrong and must be countered via psychiatric medication or direct action" (Waltz 2015:355).

How has this shift occurred? Parents have been the founders and financiers of most of the first schools and therapy programs for autistic children during the 1960s and 1970s (Feinstein 2010). Likewise, the first Portuguese association for autistic people has created in 1971 thanks to the friendship and partnership of six families (Chapter II). Although it was not already aligned with autism advocacy movement, the APPCA promoted an alternative vision to the psychoanalytic view of autism as an affective disorder. Parents no longer accepted the blame and guilt implied by the idea of autism as an affective and relational disorder. Indeed, the first etiological conception about "autism" (which is now conceived as a set of neuro-developmental disorders) affirmed that the "autistic behaviour" represented a child's defence against her rejecting mother (Bettelheim 1972). This conception contributed to spread the image of the autistic child as a being locked in a glass cage with no emotional neither relational contact with the outside world. Truth be told, mothers of autistic children were not considered by psychoanalysis as unable to love. It was rather their affective relationship that was questioned and recognized as a psychopathological element at the basis of autism insurgence. Therefore, behaviourist methods "treat" autism by helping parents to develop a healthy affective relationship with their autistic

children. Love and affective involvement were the therapeutic tools⁶⁴ for improving infant-parent interactions and became the key elements of “special parenting” practices (Silverman 2012). Engaged in full-time “therapeutic parenting” and relying on their ability to psychologically adjust to their caring challenges, bad mothers finally became (sic!) good mothers (Knight 2013).

The women I encountered strongly condemned the psychoanalytic accounts of “non-affective” mothers and described themselves as loving and skilful caregivers, relying on their maternal love and affective bonds with their child to explain their competencies and justify their commitment. As I will show in more details later, love feeds and nurtures both their special mothering’s abilities and practices, supports their advocacy fights and mobilisation, and eventually legitimates their political engagement as autism experts into the public sphere. There is a large literature focusing on women’s supposed natural attitudes as mothers - such as unconditional love, intense bond, sacrifice, and lifelong commitment (Apple 2006; Bassin, Honey, and Kaplan 1994; Laney et al. 2015; Thurer 1994). Some authors also agree that unlike mothers of non-disabled children, mothers of autistic or disabled children are more expected to publicly perform certain behaviours, such as devoting limitless time and resources while disregarding any self-interest (Hays 1996:157; McDonnell 1991) and have more strongly and intimately embodied certain social expectations about good mothering (Kingston 2007; Landsman 2009; Silverman 2012). At this regard, although invalidates the emotionally cold, intellectual, or non-affective mother described in the 20th century psychoanalytic literature, the new archetype of the “warrior-hero mother” (Sousa 2011) or “child-saving hero” (Waltz 2015:355) it is not less morally connoted. According to Sousa, warrior-hero mothers “are expected to devote limitless time, energy, and resources to their children’s development while disregarding any self-interest that may conflict with children’s needs and desires” (Sousa 2011:220). The social and moral expectations about special mothering practices, childcare involvement and advocacy commitment expose those mothers to a different but not less oppressive moral scrutiny, especially after a mass-media visibility:

“These mothers are expected to be nurturers as well as the external translators, advocates, and soldiers with expert, specialized knowledge in varied medical and nonmedical fields, including

⁶⁴ This was the case of the ABA (Applied Behaviour Analysis), a behavioural therapy first popularized during the 1970s, which provides a child with more than 40 hours per week of repetitive drills carried out with parents under the “professional supervision” of a therapist. Despite its high costs and ethical concerns regarding the stressful conditions for children, ABA is one of the most used therapies for children with ASD in Portugal and in Europe.

law, education, behaviour analysis, pharmacology, sensory integration, motor therapies, and bureaucratic minutia. These are divergent skills sets that require sizable commitments of time, money, and education. Yet the seemingly omnipresent warrior-hero archetype conveyed and reaffirmed through mass-marketing and broadened technologies indicates that there is one primary method for being a good mother of a child with an intellectual disability, regardless of cost” (idem:239).

These considerations let Sousa concludes that “the imagery of the warrior-hero mother is less of an expression of self-actualization and more aptly a continuation of a historical typification of maternal responsibility for children’s outcomes” (ivi). In this line, some authors have emphasised that full-time “professional” parenting is still accompanied by mother-blaming and guilt, a lexicon woven into the history of autism itself (Caplan 1998; Feinstein 2010). Others have noticed that while mass-media and Internet have played a central role in providing virtual social support and alternative information sources that increased women’s real sense of empowerment in the transition to motherhood, they have simultaneously contributed to validating stereotypes of mothering, maternal innate love and selfless dedication (Madge and O’Connor 2006). While acknowledging that both heroic special mothering and Internet exposure may reinforce the social expectations regards the highly affective commitment of mothers of disabled children, I will argue that they have also contributed to challenge the social perception of autism disorder and to promote a political and intellectual visibility of mothers as women.

Considering my own fieldwork, I could say that love, devotion, and patience are not merely embodied as “feminine duties”. They represent inter-relational modalities of communication and encounter with autistic people and constitute the content of these women’s passionate and political commitment as citizens. To escape mother blaming means to first recognise that it does not exist a unique way to be a mother of an autistic child, and secondly that any attempt to fit with any presumed normative figure of who a good mother should be or what she should do, can only be doomed to failure. As a woman and researcher confronted with other women’s intimacy, I realise how women as mothers are continuously rejecting and/or incorporating one or another version of “good mothering”, showing their own agency in orienting themselves to finally construct their own script and meaning of motherhood and child-rearing. Long-term child care and advocacy are *de facto* imbued in affectivity discourses and relatedness and in the following paragraphs, I will show how they acquire multiple dimensions: they inform the

transformation of mothers' subjectivity, sustain the exceptionality of the parental role within the advocacy movement and their active involvement in politics for the recognition of autism spectrum as a public health's issue.

Mothering a child with autism: between learning and intuitions

As I already outlined in Chapter III, one of the first issues parents and I talked about during our conversations concerned the experience of the diagnosis. Here I will focus on mother's accounts about the diagnosis as they often told that this event has affected their thinking about motherhood. Despite initial difficulties and frustrations, some mothers have positively welcomed an ASD diagnosis as it signified for them the "official proof" of their maternal intuition regarding their child's different development path as well as a morally-free explanation of their child's deviant behaviour. Those mothers felt unburdened and did not blame themselves for their child's diagnosis. Barbara, for instance, a mother I first met online and then encountered in person, is a very active Internet user. She used to publish autism-related posts on *Os Amantes de Saturno* almost daily and during my online ethnography, we exchanged both Facebook messages and email about her personal path as a mother of Eduardo. She described the diagnosis as a frightening experience that turned into a potentially transformative moment:

"I'm 40 now and Eduardo is 14! Long time (has passed) but I still feel that sensation (of receiving the diagnosis). [She closed and squinted her eyes while closing her arms as if she was cold] You gradually start to see the reality, you have to desist this dream of having the cute and beautiful baby that all mothers want, it's an illusion, and after much tears, after making your mourning as it is called you finally start to fight for your *real* child!"

She described the period after receiving the diagnosis as emotionally hard but also as a "stimulating phase" during which, as other mothers did, she stumbled for the first time upon local autism associations and got in touch with other parents with whom she eventually shared doubts and fears as well as found friendship and mutual support. Similarly, mothers' determination to provide education, health and social services to their autistic child and their intense dedication to getting information about autism, to manage the bureaucracy of public services and deal with educators and health professionals are not merely described as demanding and time-consuming activities. Thanks to this process, as exemplified by Laura, they also gain specific competencies and feel confident about this acquired knowledge:

“It takes time to learn how to be the mother of Oscar, you need to learn many things, always, because everything is changing, every single day science comes up with something new. I spend hours a day glued to my laptop (...) It would not be bad to get away from it all for a while, you know? I mean like take a time to read a novel or smoke a cigarette alone looking at the river. But I hate when people think I’m stressed because of Oscar. I like to know how the brain works, how technology could change the future, I always am a clever woman (...) Yes, I’m a different mother, a better one!”

As the examples of Laura and Barbara elucidated, mothering and raising a child with ASD is described as a different know-how that women learn in their everyday strengthened by their perseverance, attentiveness and dedication. For this reason, mothers of children with autism are often depicted, especially in the media, as “tireless campaigners who fought for their children’s rights with resilient determination” (Kingston 2007:16). This media representation together with a widespread emphasis on the negative psychological impacts that having a child with ASD could have on both motherhood experience and woman’s personal life gave rise in recent years to researches on autism-related topics such as chronicle maternal stress (Estes et al. 2009; Phetrasuwan and Shandor Miles 2009; Pottie and Ingram 2008; Tehee, Honan, and Hevey 2009), marital adjustment (Hartley et al. 2010; Lickenbrock et al. 2011), and depression (Almansour et al. 2013; Benson and Karlof 2009; Osborne and Reed 2010; Primack et al. 2017). Similarly, other studies argued how mothers of children with autism usually undergo more difficult and stressful experiences than mothers of children with other disabilities (Davis and Carter 2008; Landsman 2009; Safe et al. 2012; Sanders and Morgan 1997) especially because of the emotional burden associated with mother-blaming and social stigma (Gillespie-Lynch et al. 2015; Gray 2003; Grinker 2007:220; McDonnell 1991).

As I mentioned in Chapter III, almost all the parents highlighted some emotional stress in facing people’s gaze and judgment when taking their children out in public place. Children with ASD indeed look non-disabled to the public eyes and their social-interaction difficulties or their aggressive and challenging behaviours are often viewed by strangers as tantrums or as the proof of parents’ failure to raise a well-educated child. In what follows I will especially focus on mothers’ accounts because, as they often stressed out, they feel how in the public space their own behaviour as mothers is scrutinized, frustrating any attempts to prove their abilities in child raising and their self-esteem as good educators. I reported here some excerpts of interviews with two mothers with whom I more deeply conversed on this topic. Lucia, a single-mother of

Paulo (4 years old), described her frustration and annoyance regarding the public display of her abilities as a parent:

“Nobody actually understands how it’s to live with Paulo, yet everybody knows what I should or should not do! If your child makes tantrum, you can scream at him or give him a pat and people probably don’t even look at you or maybe they say, “Look this mother, she is doing well!” Now imagine me doing the same, “Oh my God! Oh, poor child!” They can get to call the police! (...) If I don’t do anything when Paulo starts to do his things then I’m stupid, I’m incompetent, I’m not able to do anything, but if I caught him with force I’m a wicked person. It’s a disgrace, seriously, they all are experts! I am the only one who doesn’t know what to do!”

Questioned on the same subject, Irene, a single mother of an eight-years-old child named Osvaldo argued:

“It’s not easy to go out with my son, I know he will do something weird (...) this results in some limitations, for instance, I don’t hang out with my friends so often as I wish...I rarely go out for dinner...at a restaurant Osvaldo doesn’t stop! (he doesn’t still for a moment) I should arrange someone to stay with him at home, but this is also too complicated. (While waling) if he suddenly wants to walk into a store, I must go in, there is no way! If I didn’t, he will jump to the ground, he will cry, he will throw a tantrum of any size...I have no choice because otherwise, we will enter in conflict (...) it’s complicated and when he will be older [she shacked her hands as saying, “I don’t want even think about it”]. It happened to me to apologize to people because of his behaviour...and I hate to feel ashamed”

Irene’s words unmask her ambiguous feelings regarding public encounters. On one hand, she feels that her skills as a mother are questioned or denied because of her child’s challenging behaviours, showing the burden of the good mother ideal whose abilities are rather demonstrated by a “perfectly behaved” child. On the other hand, she regrets to feel ashamed by people’s public gaze and worried about being a good mother, struggling to be at ease in unfitting this role. As Sara Ryan (2010) argued, sometimes the work that parents conduct in public places to make their children more acceptable within the space and to reduce the discomfort that others could experience helps to preserve the orderliness of public places, giving rise to turbulent “surveillance” feelings. I would argue that public encounters arise changeable feeling, from shame and embarrassment to strength and pride and often depend on specific situations or even parent’s “mood of the day”. In the same interview, Irene describes indeed another episode

showing her more affirmative reaction to the feeling of being “stared at” by another woman inside a pharmacy:

“You know Western movies? [she burst out laughing] I looked straight into her eyes, you know? It’s you who doesn’t understand! I do not yield to your ignorance! It is not me that has to go away, if you do not like my child’s screams or his weird noises...look for another place!”

Mothers felt compelled to “behave as good mothers” also regarding more intimate topics, and Barbara’s thoughts are quite an exemplary in this sense:

“I am proud of the mother I am and proud of my son but...I mean...what else could I say? Those mothers who aborted because their child would have trisomy 21 (Down syndrome) are considered monsters. What people might say about me! Eduardo now a teenager, but sometimes I think about him still as a baby in a certain way. Imagine if people knew that...I mean, I love him, I love him...”

Barbara is afraid to say something unacceptable, namely that as a mother she has thought that if she knew before about the condition of her son she would have eventually aborted. The good mother ideal indeed determines also what is legitimate or not for a mother to say, to do, and even to think. Being a good mother means first to love your child unconditionally. As I mentioned before, love and the child-mother affective relationship represented an object of contention of both social and biomedical gaze and key issues in the construction of motherhood associated with ASD (Silverman 2012). As some of the above excerpts demonstrate, by embodying a high-involved motherhood’s model, mothers of autistic children are the object of a renovated moral gaze. While contesting good mothering supposed norms and beliefs, they nevertheless admit feeling judged by people for their care manners and to be concerned about their ability to fulfil professional parenting expectations. In this regard, among my interlocutors, single-mothers felt especially responsible for their child’s progress and apprehensive about their mothering skills:

“I know that Oscar is not like other children,” said me once Laura “and it is difficult to deal with him, but this doesn’t mean that I failed my job (as a mother). I always repeat this in my mind, every night before falling asleep (...) I cannot stand my doubts...when I think that maybe I’m not doing things right”.

Laura, Barbara, Irene and Lucia as well as most of the mothers I encountered feel compelled to fit the image of worried and tireless mothers looking for everything that could improve their children's well-being. They also revealed to be concerned with people's judgments and revealed their will to persuade them about their good job as mothers. Some of these mothers are quite aware of the social pressures they face as mothers of a child with autism and argued how their heroism is nothing more than the flip side of the State's inability to provide healthcare and educational services for people with disabilities. Insofar as it is nevertheless incorporated, the good mother ideal represents for these mothers, another additional demanding pretension to the daily mothers' workload.

On this matter, Michael Hardt (2007) states how the perspective of the affects can be beneficial for social science research in order to understand recent changes in the dominant forms of labor and production. The author uses the term *affective labor* to refer to "gendered forms of labor that involve the affects in a central way - such as emotional labor, care, kin work, or maternal work - and that consider the nature and value of such activity both in the waged and unwaged economies, (...) recognizing that such labor engages at once with rational intelligence and with the passions or feelings" (idem:XI). As I explored in the first section of this chapter indeed women are supposed to be natural caregivers and thus expected to fulfil their maternal role through both "caring for" and "caring about" their child while fathers have in general a minor care involvement since they are usually viewed as the workers in the family. Moreover, care and maternal work are examples of what David Staples (2007) called "zero-work", which is "work not only outside of wage-work, but in one way or another, 'outside' of the definitive modes of production" (idem:119). The naturalization of this affective labour fails to acknowledge the care and mothering practices as feminine force of social production (Ryan and Runswick-Cole 2009:52) and condemns them to a taken for a granted form of work based on "gratuitousness" (Staples, 2007:126).

Indeed, intensive care, dedication to the child's needs, and maternal work, in general, are gendered activities that involve affectivity and produce knowledge. Mothers' negotiations with and resistance to the dominant discourse of the good mother, their strength in facing social isolation and stigma, their obstinacy in navigating the bureaucracy of educational and healthcare systems to get the best for their children represented practices of knowledge and not merely examples of mothers' unconditional love. During the fieldwork, I felt I was gradually nurturing a deep sense of admiration and esteem towards the mothers I encountered,

acknowledging the challenging aspects of their motherhood path, their struggles in living with, caring for their child, and thinking about her future as well as their daily determination and readiness to fight for her and claim for her rights. These aspects represented not merely maternal duties but rather personal political and moral issues that mothers face within their quotidian. Likewise, my purpose here is to show that childcare and full-time dedication are also critically thought by mothers as gendered social expectations (Christopher 2012; Lynch and Lyons 2008) showing thus a critical view of the “warrior-hero mother” image.

As I mentioned earlier, some mothers claim for the recognition of their affectivity and mothering abilities as positives values to react to good mothering ideology and mother blaming. Thus, they interpret their intensive involvement in both care and advocacy not just as a duty or as an expected responsibility but also as an opportunity to play a more active and public role. According to Ryan and Runswick-Cole (2008), mothers of disabled children still occupy a liminal position within disability studies insofar as their role as activists and their “special competence” are undervalued and disregarded, and their “actions have been interpreted as constraints within their children’s lives, limiting their opportunities and aspirations” (idem:199). As a result, the authors wish for further researches that explore how these mothers negotiate, manage and approach their daily lives, *operating* within oppressive mothering ideologies and disabling environments. To highlight mothers’ will to rely on their maternal affectivity and intuitions for these latter to be acknowledged as a relevant knowledge, I will report some ethnographic examples about their relationship with health professionals. For instance, during the afternoon she invited me to her place, Olga argued how doctors’ have just “presumptions in their hands” and still do not sufficiently understand autism’ characteristics and needs:

“My child did a lot of exams before the doctors were able to find out what he had, but in the end, doctors are those who give the diagnosis, and this is what counts! (...) but I had my doubts longer before, and they thought I was anxious! Imagine! I don’t ruminate about what I could have done better...there is no sense. Now with the therapies, it’s the same thing! if we were in Switzerland or in the United States it could have been better? No, doctors are the same everywhere, (but) mothers are different and they never make mistakes”

During our informal conversation, she frequently spoke that “despite being a housewife” she was “very curious” and “educated”. In particular, she stressed out how having a child with

autism has forced her to become smarter and to improve their qualities: “my child pushes me to wonder why things are like they are”. Likewise, Laura argued how Internet empowered her own ability to get information about autism and how this annoyed the doctors:

“Now we have Internet and we can say (to a doctor) “I read this or that, you’re wrong or it’s not as you said”, but in Portugal people are not used to complain, “Mister Doctor is the one who knows”! (...) it doesn’t mean anything if you don’t learn by yourself and understand things and to have your opinion. (...) doctors feel that now they are not still so omnipotent! I know things because I studied, I don’t have any crystal ball! Today doctors say that we (mothers) know everything, tomorrow they told you to shut up and that you are emotional (...) they are upset because parents know more, that’s their problem!”

Similarly to what Todd and Jones (2003) showed in their own research, mothers’ dealings with doctors are highly problematic especially because they feel that their worth and knowledge as mothers are continually scrutinized and questioned. Despite these feelings, they nevertheless show willing to challenge doctors’ perspectives of their children’s needs. For instance, mothers claim to own a more “authentic” knowledge about their children’s condition and a more tailored ability to detect their subjective traits and rely on maternal relatedness as a key factor that makes this difference. Mother-doctor relationship could even end in conflict as Laura’s experience shown. She provocatively considers doctors as a mere institutional vehicle for obtaining public health service provision while she complains of being merely recognised by them as a mediator or an instrument for the overcoming of his son social and communication difficulties.

The authoritative knowledge of child rearing shifted away from mothers to health professionals such as psychiatrists, psychologists and paediatricians over the course of the late 19th century and early to mid-20th century (Apple 2006). As a consequence, medical knowledge has acquired a greater legitimacy compared to that of the mothers (Waltz 2015). Olga and Laura summarized a what also many other mothers I interviewed revealed, namely that “maternal intuitions” as well as the expertise and knowledge acquired by and through mothering is an intellectual capital strategically employed “against” health professionals. Furthermore, the knowledge they have acquired from the Internet, books and scientific literature allows them to be more affirmative in their choices and less inclined to accept professional expertise as an unquestionable fact. This more conflictual and affirmative perspective is expressed by Lucia, who decided to remove his son Paulo from a therapy programme as she thought it was not worthy:

“I read a lot of books about autism, I can teach them [she is talking about therapists]! They think I don’t know anything about my son! I breastfed him from the first moment he opened his eyes, then how may they dare to know if one thing is better than another without talking to me? (...) My son will not do TEACCH classes anymore (...) it is not for the money, it’s because it’s a stress for him (...) they may think I’m irresponsible, but what do you think is better? That I do what I know is good for my son or let them decide? I’ve had enough!”

Similarly, Rute while speaking about her “unique” relationship with her 13-year-old boy Leonardo, diagnosed with moderate symptoms of autism, complained about a speech therapist who accused her to not “help” Leonardo at home with therapy and reiterated the value of her experienced knowledge as a mother:

“I’m just a parent, I know I cannot do her work [a speech therapist] but when Leonardo comes back home after hours and hours [of school and therapy] I want to play with him or do something different, right? They [health professionals] use our feelings to make us feel charged (...) They probably think I don’t have any idea about what to do because they studied on books! Well, me too! They said, “it’s years of experience in hospitals and clinics, that’s why a doctor is a doctor”, then why the hell they don’t accept what I know about Leonardo? Maybe I can say things that they will never find out!”

These quotes show how a more or a less compliant attitude towards health professionals could result from a less or a more structured capital of knowledge that mothers acquired in autism-related issues. At this regard, some mothers interpret their partners’ less participation in childcare decisions and encounter with health professionals as due to a lack of time and/or motivation to learn and keep themselves informed about their child’s autism features. While acknowledging the dissimilarity at the basis of their major availability of time is mainly due to job gender inequality, some mothers tended to rationalise this gender issue by underlying and focusing on their better learning skills in comparison with their husbands. As I already explored in the first section of this chapter, fathers’ general less involvement in childcare and education is mainly explained by several mothers as due to a different affective involvement with their child. This consideration, however, risks summarizing a vision at expense of valuing the diversity of mothers’ thoughts about fathers’ and mothers’ role. As an example, I remember at this regard the ambiguous thought of Zelia, who as a single mother, justify her ex-husband absence with his lack of time and at the same time complain about women’s excessive importance on their role as a mother:

“Husbands are not merely allies (...) and women should not promote this media image of the ‘mothers of autism’ because they don’t realize that in this way they are just digging their own grave...If fathers are not so often present it’s because they may don’t have time be present (...) Leandro’s father does what he does, I mean...to be fair I know much more things than him, I prefer to be me the one who goes to the doctor or at school, because a mother usually knows more, but this doesn’t mean that it’s just because of love or [that it’s because] they love more”

Only a few mothers explain the *motherization* of autism advocacy movement by making use of the stereotyped image of fathers as less emotional parents, who “do not feel comfortable” to attend autism support groups and “are not able to share their feelings” with other parents. This emotionless portrait of fathers is emphasized only in some cases. Overall many mothers saw father’s presence as emotionally irreplaceable especially because of their emotional support. Mothers have sometimes complained about their partners’ sort of “emotional distance” (i.e. feeling that they do not understand or minimize their anxieties and worries) and of “lack of responsibility” (i.e. feeling that fathers are always putting every decision on their child’s behalf on their hands). This is also why many women described their partners’ support as “pragmatic”, underlying fathers’ role in playing and having fun with the child after work or in taking her to after-school activities.

While recognizing how gender inequalities inevitably inform both childcare provision and household structure (namely, the “traditional” labour division between a breadwinning father and a primary caregiving mother), mothers underline that mothering a child with autism has provided them with a specific competence. Relying on both this learned expertise and that distinctive knowledge that they embodied thanks to their maternal love, attentiveness and intuitions, mothers claim to be recognized as meaningful and relevant experts about their child’s condition. In the following paragraphs, I will survey the association between women, motherhood and affectivity and then focus on the role of affectivity in mothers’ advocacy on behalf of their child. My purpose is indeed to explore more deeply mothers’ emphasis about their public role as advocates and activists, underlying how the gendered traditional roles of a “public” father and a “private” mother are in a certain extent subverted. This attention in my fieldwork to the interlacing between affectivity and advocacy practices would attempt to show that - at least compared to the past - the increased access to specialized knowledge through the Internet, the acquisition of more awareness and confidence in their affective and emotional

abilities as well as the active participation in advocacy movement have given to mothers an undeniable broader visibility and agency as women and citizens.

Mothers as “active social agents” and “experiencers”

According to the pioneering work of Adam Feinstein (2010), the birth of autism advocacy groups during the 1960s and 1970s represented a deeply changing event regarding disability rights, motherhood normative prescriptions and the dynamics of power between parents and health professionals. Motherhood and mothering work were no longer confined to the private and intimate space of the home, instead, they became negotiable fields of knowledge within both the scientific and public spheres. Among the parents, there were especially the mothers who joined mutual support and advocacy groups on behalf of their disabled children to fight for their rights. Thanks also to new media platforms, mothers started sharing their expertise with other mothers, building a community of shared practices and contributing to a new sense of assertiveness (Johnson 2015; Morrison 2011). They become a model for other mothers by teaching them how to cope with the healthcare system and educational services and by encouraging them to be more empowered in their relationships with health professionals and educators (Ryan and Runswick-Cole 2009).

The figure of the warrior-hero mothers, which replaced the “weak” and “cold” mother of a child with intellectual disabilities (Caplan 1998; Landsman 2009) especially the “autistic” one (Bettelheim 1972; Grinker 2007), took place under those circumstances in both medical scholarship and public opinion. As I discussed earlier, this new archetype reiterates the moral and social responsibility of mothers for the well-being, growth and evolution of their children as well as for the warranty of their rights. At the same time, however, the commitment of special mothering and advocacy has been also positively embodied by mothers as a renewed confidence in their own skills as mothers and knowledge as autism advocates. Heroism, full-time involvement, dedication and love are used by mothers as topics of a narrative of self-presentation that depicts them as “models” and “fighters”. Mothers operate indeed within the private and the public spheres not as mere victims of a gendered ideology of motherhood but as “active social agents” (Ribbens 1994:205–6).

According to Ryan and Runswick-Cole (2009), the “high level of advocacy” of mothers of children with ASD translates into a form of activism, which is “a mechanism for expressing, in a ‘selfless’ way, the mothers’ aspirations and needs. Activism allows mothers to ask for help

while at the same time managing their image as the ‘selfless carer’” (idem:51). Mothers’ struggles on behalf of their children triggered a broader social battle against enduring inequalities and exclusion of disabled people. I remember, in this regard, the emphatic words of Rute when she once pointed out how her heroism was beneficial not just for her son Leonardo but also for the society at large:

“Somehow all the mothers are one...like, I mean...a mother is undoubtedly a fighter for her child, for her to be treated with fairness and dignity (...) My friends and my family say I behave like a warrior when it comes to anything related to my son because I’ve never been afraid to give my voice to claim for his rights and to speak about autism, about all the disabled people in this country (...) I have already been a spokesperson for other mothers too, I’m not flaunting my force, I fight also for you, you and you” [pointing to imaginary people]

Mothers become activists as they employ the skills and knowledge acquired to help other children and families and to campaigning for other mothers and for the larger society (idem:43). Love as well as commitment and dedication - like I showed earlier with regards to special mothering practices and maternal work - emerge as leitmotifs of mothers’ narratives also with regards to their campaigning for social change. In diverse lived moments of field interactions with mothers, I felt the importance - and the political and intellectual duty - of acknowledging women’ use of affectivity discourses to validate their public role as autism experts and disability rights’ advocates. I also felt how it was relevant to them that I could appreciate their awareness of the political value of these discourses and their stance not just as mothers but also as engaged citizens.

These first considerations inspired me to further explore the association between women, motherhood and affectivity, and it reveals to be rich in powerful ambiguity and contradictions. For instance, several feminism thinkers conceived motherhood as a self-sacrificing choice made by women who unwittingly accomplished a patriarchal duty (de Beauvoir 1977; Chodorow 1994; Firestone 1970). Patriarchal ideology shaped women’s desires and created the “good mother” myth (Margolis 1984; Thurer 1994), which was viewed as a Western historical and cultural construction to be critically subverted (Bassin et al. 1994; Trebilcot 1983). According to Hays (1996), “good mothers” should have to dedicate their life to child-rearing, which requires “the day-to-day labour of nurturing the child, listening to the child, attempting to decipher the child’s needs and desires, struggling to meet the child’s wishes, and placing the

child's well-being ahead of their own convenience (idem:115). Approached in these terms, motherhood has been represented as a feminine accomplishment of a gendered system of domesticity (Williams 2000) based on an "intensive mothering" ideology (Christopher 2012), which swallows up the woman as a human being. In the same fashion, in her book "The Paradox of Natural Mothering", Bobel (2001) reports how women who positively reclaim "home and family" as natural and satisfactory achievements and embark on the path of full-time mothering are just consciously complying with gender ideology and patriarchal oppression.

Feminism thought kept addressing gender equality concerns with regards to workplace, sexuality, and family. But while keep on deconstructing the supposed "naturalness" of motherhood and any kind of biological reductionism, some scholars recognised the need to "reconceive" motherhood (Umansky 1996), to validate women's desire to be mothers and even to celebrate motherhood as an empowering experience (Rich 1986). Mothering practices and motherhood itself started to be acknowledged as historical and political issues but also as deeply personal and emotional practices (Levy 1983). Despite these efforts, motherhood still resists to any definition:

"Whether idealized in symbol and story, conferred as right, privilege, or responsibility, or examined for its social, cultural, and psychological consequences, the subject of mothers and mothering elicits strong opinions, powerful emotions, and intense commitments" (Barlow and Chapin 2010:324).

For instance, Scheper-Hughes studied maternal sentiment by focusing on the effects of the everyday experience of scarcity, sickness and death on the lives of the women and children of a hillside favela in Northeast Brazil. The author explored how class relations and social violence affected women bodies, emotions, desires and needs as mothers. She eventually argued that because of extreme conditions of hunger, scarcity and infant mortality, maternal detachment and neglect became patterns of nurturing in the community (Scheper-Hughes 1985) so that "death without weeping" ended up being the controversial title of her ethnography (Scheper-Hughes 1993). Motherlove, as conventionally understood, was thus something of a bourgeois myth, a luxury for those mothers who can reasonably expect that their infants will live. In her long-term ethnography, she showed how mother love's manifestations are always shaped by social and economic conditions while cultural beliefs reinforce them. Following these findings, also Farfan (2005) focused on the cultural construction of maternal sentiment by considering

the social conditions in which mothers live, their work, their kinship networks, and the ways in which they define motherhood. The two authors reveal the cultural construction of sentiment and motherhood by illustrating how maternal sentiment depends on social and economic conditions of life. What results thus is an effort to neither romanticise motherhood nor isolates women as uniquely responsible for constructing and manifesting maternal love.

Following the considerations advanced so far, mothers as gendered individuals are subjected to diverse regimes of socialization as well as to composite strategies of “motherization”. Another way of thinking about this topic is to acknowledge that beyond biomedical knowledge, patriarchal ideology and social expectations, also family is a relevant space in which maternal love is constructed and performed. The family represents indeed one the institutions through which - according to Foucault (Foucault 1965, 1977; Taylor 2012) - the State is able to spread, extend and reinforce its disciplinary practices. However, I would like to strengthen the idea that thanks to the volatile quality of control’s practices, disciplinary power itself has a transformative nature. In other words, in trying to model individuals’ habitus, any disciplinary model always leaves an open space for personal actions. Following this line of reasoning, mothers should be conceived as (un)disciplined subjects, whose supposed acquiescence to motherhood’s social representation and rules is circumvented, denied and contradicted by their idiosyncratic behaviours and attitudes. As expressed by Clough (2007), “the target of control is not the production of subjects whose behaviours express internalized social norms; rather, control aims at a never-ending modulation of moods, capacities, affects, and potentialities” (idem:19).

In my view - which is shaped by the way women I encountered in my fieldwork *do* mothering - motherhood is a corpus of embodied but also disobeyed biopolitical strategies and social expectations. Mothers are first *individuals* who differently respond to both cultural constructions and socially desired values regarding “what means” and “how is” to be a mother. In this way, being a mother should correspond to what each woman is “doing” as a mother. By focusing on what humans do, it means to understand why and especially what move people to do what they do (D’Andrade and Strauss 1992). This attention to the operational aspect of motherhood is crucial in that doing motherhood is, like “doing gender” (West and Zimmerman 2002), a practice that is reproduced, negotiated and subverted through social interactions and performative acts (Butler 1988:519). I think important in other words to emphasize that motherhood, as any other human experience, resists to any strict codification. As well as other

gendered behaviours shaped by cultural models and socio-political ideologies, it is never robotically learned. Mothers eventually do “internalize” some “good mother(ing)” social expectations as well as do refuse some others (Strauss 1992:4). As I already pointed out, intensive mothering, dedication and especially maternal love shape the way in which mothers of children with ASD present themselves but their narratives reflect also their personal goals and expectations, attachments and desires. Their self-presentations are not just “replicas” of the sociocultural model of special motherhood or “a direct precipitate of cultural constructs” about good mothering (idem: 1-2). As a result, mothers consider themselves neither merely instruments of their children’s needs nor the evidence of fitting well in the role of a good mother of an autistic child.

Is it then possible to do not fall into a trap of considering motherhood just as a sacrifice and a form of patriarchal control of women’s life or as an empowering choice full of rewards for raising, caring, and bearing children? In a certain way, motherhood is undermining female empowerment when women are asked to give up their career or personal achievements to find fulfilment in the name of motherhood. At the same time, however, I do see mothers who critically acknowledge how, beyond the sacrifice of full-time childcare, they are dedicating part of their lives to fight for disability rights on behalf of their own children as politically involved women. Rather than reducing women’s idiosyncratic representations to mere traps masterminded by a patriarchal society, I think valuable to consider motherhood, special mothering practices as well as maternal affective involvement as contextual and variable acts performed by women as “experiencers”. As a mother, a woman is indeed always a “self, actor, agent, an experiencer” (Chodorow 1994:4) and not a monolithic body. Agreeing with this view, several feminists scholars developed a feminist moral theory of care and motherhood which neither romanticises women’s experiences of care and motherhood nor reduces these experiences to selfless or self-sacrificial acts (Green 2011; Rogers and Weller 2012:5)

For what concern my own fieldwork, the women I encountered interpret their affective involvement in autism advocacy groups as both an “inevitable” consequence of being a parent of a child with autism as well as a choice of political commitment for a better society. Indeed, not all mothers became necessarily advocates. Fighting for autism awareness and for disability rights is an option that synergistically coexists with the idea of publicly expose yourself as a personal fulfilment, that is to become an “active citizen” committed to social change. As many other mothers do, Irene, Olga, Barbara and Rute live, understand and explain their engagement

in autism advocacy also as good citizenship practice. School inclusion, inclusive workplace policies, health care and therapies access, social and cultural awareness about disability rights are just some of the issues of their activism. Special motherhood and autism advocacy need thus to be understood not just as good conducts produced by socio-cultural disciplinary ideologies but also as personal projects and ways of playing the mother role within the public sphere. As feminine political actors, those women are critically aware that their role as an advocate is linked to the role that society prescribes to them as mothers. Within this unequal and gender subjectification, they do not escape the confrontation with issues such as work dismissal, social inequalities and politics of exclusions. Instead, they attempt to continuously construct their “own script” of being a mother of a child with autism, also relying on a “social activist position” (McDonnell 1991:73). In this way, they eventually overturn their own specific struggles into a collective call for social change. I think that this more complex view of mothers’ accounts can contribute to promote them as engaged agents and to acknowledge a vision of motherhood more in line with a feminist point of view (Green 2006, 2011). Then, the assumed and embodied feminine characteristics of motherhood - instinct, love, resilience, dedication and so on - represent “performed emotions” and in my ethnographic cases, they’re used as a political capital to support special mothering efforts as well as to sustain, guide and legitimate mothers’ activist role and their commitment to a better society.

The political force of affectivity

As I described so far, maternal love has been a contentious object of the medical gaze. While for psychoanalysis mothers’ emotional unavailability engenders child’s autism as a defence, behavioural approach started to look to mothers’ love and dedication as a resource for healing mother-child attachment and improve child’s development and social skills. I have also explained how the spread of autism advocacy movements since the 1980s contributed to change the understanding of the parental role so that affectivity acquired a new semantic and political meaning especially for mothers of autistic children. According to activist parents, autism is not a “shell” in which the child is trapped inside to protect herself from unaffected mothers. There is not a normal child hidden inside autism disorder. The epistemological shift in understanding autism as a highly variable neurodevelopmental syndrome is also the result of the opposition and critique that parents moved to delegitimize the idea of autism as an affective psychosis as well as of their resulting huge financial support for genetic and neurologic research. This epistemological shift represented one of the first historical victories of parents’ activism together with the improvement of assistance programs, therapies and medical services.

Psychoanalysis became to be strongly criticised for spreading mother blaming assumptions while parents fought to be recognized as authoritative experts about autism issues.

In what follows, I will interpret mothers' political and social mobilisation as ingrained in affective ties and argue that affectivity is used as a political capital. My idea is that by publicly employ their affective discourses in autism advocacy, mothers are exerting leverage on and thus also reinforcing the political value of love. In doing so, mothers are constructing a model of political commitment that is fed by their own affectivity, which helps them to legitimate and sustains their role as engaged citizens. Their specific goals represent, after all, political demands for a general social change of society. For instance, in advocating for their children' inclusion in public education or for their rights to housing and to work, mothers are contributing to reverse those social inequalities and precarious conditions about reaching adulthood which affect many people with disabilities. Similarly, their campaigns for implementing social measures that rely upon people's different abilities - rather than on public assistencialism, which transforms solidarity institutions into long-life vicarial subjects - represent a broader and challenging social and political aim. As I previously illustrated, mothers have become leading players of a public use of affectivity as political capital, thanks to a stronger critical awareness of normative and gendered discourses about good mothering, a renewed confidence in their abilities to respond to their children's needs and a broader understanding of autism spectrum itself - made especially possible by a facilitated access to specialist knowledge through the media and the Internet.

In order to grasp affectivity as a political capital, I chose to interpret mothers' emotions through a perspective that acknowledges the capacity of emotions to become political motives, namely the capacity to affect us and other people, transforming our mutual capacity to act in the world (Ahmed 2004; Clough 2007). Terms such as "affect" or "emotion" can mean very different and sometimes opposite things. For this reason, while writing about emotions, I felt compelled to first situate myself within the different theoretical frameworks about emotions. Indeed, because of the richness of their meanings and the amplitude of their "action range", it is so difficult and puzzling to define what emotions are. As they slip away to any attempt to be enfolded in a satisfactory definition (Gregg and Seigworth 2010), any definition of emotion is specific and it usually suits the field of a single discipline. Following Pussetti (2005b), the more useful way to get out from this impasse is to accept the vagueness and polysemy of the notion of emotion according to Wittgenstein's concept of family resemblances (idem:28). Concepts and notions

are, above all, daily used by people insofar they are useful for them to communicate their ideas and achieve their purposes. Consequently, as a notion “emotion”

“takes its meaning from the local concepts that people use to make sense of their existence. Common language, which covers a range of complex situations an individual can experience, seems to be more appropriate to mirror the nuances of the concept of emotion rather than the scientific discourses, which are apparently more sophisticated, but whose definitional intent often results in strict conceptual distinctions inappropriate to grasp the flow of daily life” (idem:26-7).

Emotions are more than bodily responses or reactions to physiological modifications or external events. They are certainly felt within and through a body, but this body is not merely conceived in its material texture or as a container that houses emotions. Emotions are dialogically linked with the local context in which we live and where we are continually educated, and they also depend on our personal memories and time contingencies. The “bodily” texture of emotions is therefore linked to the ways in which our mindful body dialogues with the social and cultural context in which it is embedded. For those reasons, several important works within the field of the anthropology of emotions endorsed the necessity to understand and explore emotions as social and cultural practices by locating their meanings within the familiar background of people everyday life’ uses (Abu-Lughod and Lutz 1990; Lutz and White 1986; Rosaldo 1984). I will not investigate, however, emotions as cultural constructs. While my interlocutors unquestionably spoke “about” and “through” emotions, I am not interested in addressing their narratives as these were discursive configurations to understand their cultural background in a strict sense. Following Veena Das’ reading of Wittgenstein (Das 1998), language is an experience and not simply a tool or a vehicle to communicate our culturally acquired interpretations of the world. Language thus is not uniquely verbal but represents a bodily and sensual companion that allows us to exchange our experiences and memories. Similarly, emotions as experiences could even be not verbally communicated and yet they are nevertheless corporeal since, beyond verbal language, there exists the sensitive and corporeal capability of human beings to say and communicate emotions to others.

A manifold description of emotions (Clough 2007) - as both expressive and interpretative ways of being in the world - considers individuals as cognitive, affective and sensual beings imbricated in their everyday performative actions and discourses with others. In other words,

people - as dynamic social subjects - do not just “feel” or “speak about” emotions in socially prescribed ways, they are also performing the emotions they embodied. This performativity belongs to discourses and practices, words and actions so that both can illustrate the affective nature or texture of our daily life activities, interests and concerns. Emotions thus say something about the ways in which we position ourselves in the world and thereby they inform our disposition towards things and situations, namely our involvement with social events and society. Indeed, if emotions communicate and share our purposes and interests to others, they can be viewed as “mutual influences” that take place between bodies and change our way to respond to our present actions and to shape the future ones. My attentiveness towards emotions lies exactly on what they do, how they circulate among people and how they allow people to connect each other.

Emotions can reveal our motivations and desires as well as our fears and tensions because they are part of those power relations and social institutions that permeate our social space. Notably, Gould (2004) introduced the idea of a dialectic link between emotions, politics and political engagement to situate emotions at the intersection of culture, society and power. Eventually already from the mid-1990s both human and social sciences have already undertaken an “affective turn” (Athanasίου, Hantzaroula, and Yannakopoulos 2008; Clough 2007), namely an approach willing to overcome a purely individualized or strictly socio-cultural interpretation of emotions. By acknowledging the limits of any constructivist account of emotions, scholars no longer read the individual’s body and identity as *tabulae rasae* in which society inscribes its norms and meanings and emotions simply find their place (Gregg and Seigworth 2010). Instead, emotions started to be primarily acknowledged as forces that mutually affect people in their everyday life, underlying how the relation between emotions and politics or power resides also in their capacity to change our ability to act and to relate to others (Clough and Halley 2007).

In her introduction to “The Affective Turn” (2007), Clough wrote to use the term “affect” to refer to the “bodily capacities to affect and be affected or the augmentation or diminution of a body’s capacity to act, to engage, and to connect” (idem:2). This reading of emotions as affects is influenced by Spinoza’s thought about *affectus* to the extent that it underlines the mutual openness of human beings to shape and be shaped by others. According to Gilles Deleuze (1978) - who brilliantly studied Baruch Spinoza’s main concepts in his own “Courses de Vincennes” (the lectures he did at the University of Paris VIII at Vincennes) - the Dutch philosopher explored how “our power of acting or force of existing is increased or diminished

in a continuous manner, on a continuous line (...) *Affectus* is thus the continuous variation of someone's force of existing (and is) determined as the continuous variation of the power of acting" (idem). He further argued how Spinoza's affect can be defined as the increasing or decreasing capacity of a subject's capacity to act and think, that is the force that modifies "the potential of *vis existendi*, the force of existing, or *potentia agendi*, the power [puissance] of acting" (idem). As forces concerned with our potential and capacity to act, affects are thus deeply connected with the idea of transformation, with the changing capacity of the body to be engaged with the world, with the capacity to do actions that transform sociality and power relations. We are, in other words, "affecting bodies" and "affected bodies". But how affects turn out as transformative elements? Massumi (2002) argues that to understand Spinoza's affect as a transformative element, we should parallel the term affect with "intensity" (idem:27) that is the variation from a preceding state of being to a new one that implies a transition - called by Spinoza himself "duration".

Since the quality of the emotions understood as "affects" is to constantly increase or decrease our capacity to act, they trigger also a transformation of people and of their values, intentions, or interests. In a way, this quality echoes to me with the Gramscian reading of politics, which deeper and intimate meaning, as I have explored earlier, lies in the power to transform subjectivities (Gramsci 2011 [1971]). By following Deleuze's approach to subjectivity and his reflections on the transformative potential of *becoming*, Biehl and Locke (2010) acknowledge the relationship between socio-political and subjective transformation. These considerations allowed me to argue that mothers of autistic children politically employ the lexicon of affectivity in describing their involvement and commitment to autism advocacy. This lexicon functions as a transformative element for both their subjectivity and ideally for the broader society since the public display of mothers' affectivity is willing, in my view, to sensitive people about disability issues.

I explored mothers' use of emotions - such as maternal love, dedication, force - in both discourses and practices of autism advocacy through the lens of affectivity. The Spinozian notion of affect allowed me, as I described in this last section of the chapter, to acknowledge emotions' ability to affect people's subjectivity and to increase their capacity to act, that is the agency. In this way, I suggested that mothers' use of affectivity has a political value and impact because emotions trigger a mutual relationship between people. This focus on affectivity also allows me to understand that emotions as maternal love always imply a transformation of a

status quo. Affects have indeed a procedural nature, they arouse a process of transformation, they inhabit the transition (duration) of a situation to another one and accompanied thus the path of all our life's changes. By using affective discourses within their everyday campaigns as well as more mediatized advocacy events, activist mothers share their motives and preoccupations and solicit people to respond. Love and commitment are indeed positive political motives - which according to a Spinozian view means that they increase the force of existing and the power of acting - and thus represent catalyst emotions that support and motivate people. By publicly employing affectivity as a political motive, activist mothers are willing to solicit society to be affected by and to respond to their campaigns of mobilisation.

Love as *affect* that moves people to social change

Mothers' commitment to autism advocacy is deeply intertwined with affectivity. My idea is that the relation between affectivity and advocacy is a positive one, in the sense that it is productive and transformative. In this last session, I have illustrated how mothers publicly employ maternal love and dedication to the child to support and strengthen both their discourses and practices of special mothering as well as to explain the distinctiveness of their involvement in autism advocacy movement. Supported, motivated and driven by their love, mothers search, obtain, and even distribute to other mothers their knowledge and experiences in facing with their autistic children. Maternal love is embodied as the purest and deepest doorway to knowing a child's needs and abilities and political reason that explain and legitimise mothers' engagement in advocacy. Maternal love is exposed and employed in virtual communities, media and within the public space as a form of intellectual and political capital. Under those circumstances, advocacy can be understood as a form of "emotionally imbued" commitment to social change that intertwines maternal love and political involvement and turns mothers into powerful examples of committed citizens.

Emotions represent ordinary, yet extraordinary, aspects of human life and they are entangled in our daily practices as well as discourses. In my fieldwork, I recognised mothers as individuals who have not passively embodied the social and gendered expectations regards special mothering. On the contrary, they are constructing and performing their own script of special motherhood. I argued indeed to consider mothers as experiencers and active social agents to avoid any immutable hierarchy between the human subject and the normative power and to highlight instead the ability of human beings to achieve their own idea of self, in a continuous and dynamic process of subjection and subjectivation, of signification and subversion, of power

and pleasure. In my ethnography, the women I encountered were lucidly subjected to their “emotional role” as mothers of children with autism and at the same time, their affectivity played a powerful key role in constructing their public role as advocates. On one hand, unconditional dedication, maternal love and the ethos of sacrifice represent a set of expected emotions and behaviours establishing a “good mother profile”, on the other they are also actively cultivated by mothers as means to legitimate their role as advocate and to finally raise awareness of the challenges faced by people with disabilities and the need to enhance their social inclusion at all levels of society.

In this chapter’s last section, I tried to underline how autism advocacy is so deeply construed by and connected to maternal love and kinship that parental affective bonds seem to be a *conditio sine qua non* for advocacy commitment. As I have explored, the political value of mothers’ affectivity lies in the “in-between-ness” of emotions themselves, namely in its power to act and be acted upon. Affectivity is, in other words, a modality of inter-relationship, a form of mutual influence between people and then a political tool. The affective content of advocacy practices and discourses and the unique emotional relation that mothers have with their children contribute to spreading a vision of love as a political motive. I stated the importance to consider emotions as performative and productive forces because they actually have the power to transform and shape people’s interests, motivations and actions (Ahmed 2004; Gould 2004). Mothers claim for the relevance of love as a value of public significance and call to expand understandings and recognition of disability rights beyond the private, domestic or personal arenas. Indeed, mothers’ affective engagement aims to bring autism to light and to promote disability rights in the public space to sensitise also people who are not directly related to people with autism. There are not calling for compassion, rather they ask society to be willing to be affected by other people’s needs and requests and to move towards certain ideas and ideals of social egalitarianism and social justice.

Chapter VI

From techno-companions to a post-human vision of becoming A call for a broader citizenship

In this chapter, I will first explore the link between technology and autism. I will briefly describe how the Internet and its increasing use and availability, played a key role in the birth of the neurodiversity movement, by allowing the so-called “high-functioning” autistic people to speak for themselves and advocate for their own rights. Then, I will more deeply present my ethnographic data about the use of mobile devices and augmentative and alternative communication (AAC) programs by children with autism and learning and communication difficulties and discuss the ways in which these tools are assumed to improve their social skills and positively affect their relationships with other people. These two examples show the different purposes for which technology can be used by people with autism and reveals again the variety of autism spectrum disorder in affecting a person’s ability to communicate and to relate to others. Indeed, while the Internet is thought to be a tool of empowerment and of citizenship’s expression for those people with autism who do not have learning impairments, AAC technology can provide children with severe speech and language disabilities with an opportunity to address their communication needs. In this second case, technology represents an assistive tool that could eventually help them to express their own intentions, alleviating some issues regarding their (often) profound intellectual disability. Technology shows how its use produces different kinds of empowerment. After having explored the need for critically interrogating the notion of “human”, I will secondly explore how to think citizenship when referring to those people whose autism represents an intellectual disability and whose cognitive impairments don’t allow them to exercise a full citizenship.

Techno-companions

Nowadays our existence is daily interlinked with technological innovations, such as the Internet, apps and interactive programs, and technological artefacts, such as computers and tablets with multi-touch screens and virtual keyboards. But what is the role of these technologies for people with autism? Before presenting in this section my ethnographic report about the different purposes of technological artefacts’ use by people with autism, I would like to clarify that I do not consider technological devices merely as tools used to achieve a scope

or to execute an action. Rather, I explore and address the relationship between techno-devices and humans as always tangled in a mutual embodiment process. Technological artefacts represent indeed the “co-subjects” of that dialogical process that is our subjectivity and our ways of manifesting its forms. This is why this section is titled “techno-companions”.

Internet as tool of communication and empowerment

Among the different technological breakthroughs that have been used to improve the quality of life of people with autism, the digital one holds important implications. Since individual with autism show difficulty to engage in face-to-face interactions (Baron-Cohen et al. 2001), scholars have underlined how the Internet and virtual communities allow them to interact within a familiar setting, such as on a computer in their own home, avoiding the discomfort from getting over-stimulated by public, less controllable and unfamiliar environments (Happé 1991; Mitchell 2003) or by their own hypersensitivities to noise and light (Frith 1989). The introduction of the Internet has also encouraged them to communicate with each other via chat rooms and discussion boards, alleviating the anxiety due to some features of social interaction such as “motor expression, tone of voice, and interpretation of conversational partners’ emotions, with which they have some difficulty” (Jordan 2010). Moreover, virtual communication permits to “take time” and to elaborate a thought or an idea more than one time before “send” it to an interlocutor as well as to avoid to over-control outward behaviours such as repetitive movements and stimming that might be regarded as inappropriate in the public space (Biever 2007).

According to Bagatell (2010), besides the broadening of the autism spectrum category and the influence of disability rights movements, the Internet represents the third historical factor that significantly contributed to the emergence of an “autistic community” and that played a key role in allowing autistic people to speak for themselves and advocate for their own rights (idem:33). The online growth of autism self-advocacy organizations and virtual communities pioneered by individuals with autism allow them to voice their demands and to spread what it is now commonly known as the neurodiversity movement. This virtually begun with Jim Sinclair’s speech “Don’t Mourn for Us” at the 1993 International Conference on Autism in Toronto that come to be acknowledged as the symbolic founding of the autism community and self-advocacy movement. In this speech, Sinclair, who is himself autistic, defined autism as “a way of being” and a “pervasive condition” that it is impossible to separate from a person insofar as it “colors every experience, every sensation, perception, thought, emotion, and encounter”

(Sinclair, 1993). He provided a significant counter-narrative to the view of autism as a tragic tale and warned parents about how their fear and pain of “losing a child to autism” revealed their illusory expectations about the child they wished to have. During the 90s autistic people started to led autism associations and to fight for their self-determination and for autism’s social acceptance so that Internet was soon been considered “for many high functioning autistics what sign language is for the deaf” (Singer 1999:67).

The neurodiversity movement questions the widespread conception of what does it mean to be normal and live a meaningful life, and the very possibility that a person can be considered as socially functional. Besides this, activists advocate for the recognition of autism as a neurological difference resulting from normal variations in the human genome (Jaarsma and Welin 2012), showing the range of different ways in which humans can experience and perceive the world. Autism spectrum thus represents a pattern of human diversity rather than a mental illness or a psychiatric disorder. A new awareness of human difference, resulting from the uncovering of an ever-wider variety of brain wiring that neuroscientists and neurologists interpret as another range of differences among the humankind, supports this epistemological shift. The renewed neurologist Damasio claims in this regard to embracing brain differences, like body differences, with esteem:

What all of our efforts in neuroscience are demonstrating is that you have many peculiar ways of arranging a human brain and there are all sorts of varieties of creative, successful human beings. For a while, it is going to be a rather relentless process as there are more and more discoveries of people who have something that could be called a defect and yet have immense talents in one way or another (Harmon, 2004)

Behavioural conformity represents thus one of their crucial concern. Most of the therapeutic programs for children with autism - like ABA therapy - aims at teaching how to mimic proper behaviours such as maintaining eye contact and answering appropriately during a talk while teaching how to “avoid” behaviours seen as socially problematic but inherently autistic such as “stimming” (self-stimulating behaviours such as rocking and flapping). This therapeutic focus on behavioural compliance forces children to conform to socially accepted social habits and behaviours. According to neurodiversity activists, this suggests that there is something inherently wrong with people with autism as human beings. If it is impossible to separate an autistic person from her own sense of self and peculiar manners of perceiving and processing

the world, as Sinclair's speech argued, thus any attempt to mimic, assimilate and reach normative behaviours represents - and is experienced as - an intimate coercion of the true autistic self. Normative behaviours, in other words, represent a threat to the many forms and configuration in which humans can experience emotions, perception and interpersonal relationships.

A well-known assertion by autistic activist Amanda Baggs emphasises the violence that so-called "neurotypical world" place on autistic people's way of life:

A world in which autistics are expected to submit to being "repaired" (...) are subjected to abuse, ridicule, and punishment for being who we are (...) are given dangerous psychiatric drugs and treatments which attempt to force neurotypical behaviour on autistics. This is a world where autistics who manage to mimic neurotypical behaviour well enough to "get by in the world" are often plagued by deep emotional and self-image problems because of the discrepancy between who they are and what they appear to be (...) [and they are] punished every day for being real, and rewarded for being false (Baggs n.d.)

In the early 2000s, a hilarious website called the Institute for the Study of the Neurologically Typical (ISNT) - now no longer active - sought to satirize neurotypical people (NTs) and "their cultural fascination with deviance" by investigating neurological normality disorder (NND) or neurotypical syndrome:

"Neurotypical syndrome is a neurobiological disorder characterized by preoccupation with social concerns, delusions of superiority, and obsession with conformity. Neurotypical individuals often assume that their experience of the world is either the only one or the only correct one. NTs find it difficult to be alone. NTs are often intolerant of seemingly minor differences in others. When in groups NTs are socially and behaviourally rigid, and frequently insist upon the performance of dysfunctional, destructive, and even impossible rituals as a way of maintaining group identity. NTs find it difficult to communicate directly, and have a much higher incidence of lying as compared to persons on the autistic spectrum. NT is believed to be genetic in origin. Autopsies have shown the brain of the neurotypical is typically smaller than that of an autistic individual and may have overdeveloped areas related to social behaviour"

The neurodiversity movement illustrates once again what I have underlined during this thesis, namely that autism is not a single category but a variety of conditions and ways of experience

the world. At this regard, Happé (1999) suggested that the so-called high-functioning autism (HFA) can be characterized as a different cognitive style rather than as a cognitive deficit. Similarly, Baron-Cohen (2000) considered the term “difference” as a more neutral, value-free, and fairer description than terms such as “impairment”, “deficiency” or “disability” that should only apply to the so-called “low-functioning autism” (LFA) and may need to be retained for HFA as long as the legal framework provides financial and other support only for individuals with a disability. The issue at stake here, it is whether society should help people with “atypical” personalities or behaviours to cope and fit with most other “typical” people or should encourage “typical” people to respect and learn how to interact with “atypical” people. Indeed, even though neurophysiology science may identify a connection between distinct brain patterns and some behaviours, only society at large is then in charge to deal with and accommodate human differences.

Even if in my fieldwork I did not address directly the autism self-advocacy Portuguese movement, nor I had the opportunity to encounter people with so-called HFA or Asperger, I have nevertheless observed that a minority of parents agree with neurodiversity’s claim. Some parents of children diagnosed with autism and cognitive delays support a “diversity” approach and the idea of autism as a difference, rather than a deficit or a disorder. To them, the recognition of a biological basis for their children’s difficulties (even though at present there is not one definite organic cause for autism) marked a shift from an idea of autism as a “moral diagnosis” to a medical one. Olga, for instance, is aware that a redefinition of autism as a neurological difference is possible for just some of the set of conditions included among the autism spectrum. Notwithstanding, she believes that the neurodiversity is “a kind of philosophy” that together with neuroscience developments is crucial for autism to be no longer associated with deficiency or defectiveness and can be important in future for deconstructing disability’s social inequalities. Other parents, like Pedro, take inspiration from what the Internet and online autism community accomplished for turning society more tolerant towards autism: “a real tolerant and open society” - said Pedro - “would try to understand and respect all people with autism, even those with the oddest behaviours and not just the Asperger ones”.

My fieldwork gave me the opportunity indeed to acknowledge that neurodiversity demands and claims can be tricky when addressed to those people who are “severely” autistics. As an example, for Barbara, mother of 14-year-old Eduardo diagnosed with a very severe form of autism and cognitive delay, autism does not represent necessarily “something to preserve”. The

possibility to detect autism in future with brain scanning technology such as fMRI or any prenatal testing will represent for her a chance for “eradicate” autism, a consideration that most other parents I interviewed found repulsive and violent. Autism as a neurological difference represents indeed a still controversial issue (Baker 2006; Kapp et al. 2013) and raise real-life challenges, as Robertson (2010), himself an autistic researcher, pointed out. Similarly, the boundaries between society’s expectations regarding behavioural compliance and people’s right to self-determination and to take part in society according to their own peculiar abilities are the object of ongoing debates.

Thanks to the Internet and online communities, autistic self-advocates unveil the social and political barriers that society creates with its normative discourses and social expectations about what it is like to be a “functional being human”. By raising awareness about neurodiverse people, they aim at creating a more inclusive future society able to counteract the structural inequalities lived by autistics themselves and to allow them to live and develop as individuals according to their own way. This sense of “peculiarness” and the usage of the Internet as the main virtual arena in which much of the work of advocacy takes place in have had a crucial role in the emerging of a so-called online autistic culture (Davidson 2008; Davidson and Parr 2016; Dekker 1999). As any other community with its own shared meanings and practices, the autistic community defines itself as a subculture or a counterculture in opposition to the dominant neurotypical culture.

The search for an identity has also led some self-advocates to publicly express their will to be considered like aliens, the quintessence of otherness: “communicate with us as if we were aliens, not as if we were damaged versions of yourself” (Baggs n.d.). The reference to aliens has been also employed to sensitize parents about their child’s impressive difference: “look at your autistic child again and say to yourself: This is not my child that I expected and planned for. This is an alien child who landed in my life by accident” (Sinclair 1993). The metaphor of the alien is sometimes conversely associated to the broader society:

“Each of us who does learn to talk to you, each of us who manages to function at all in your society, each of us who manages to reach out and make a connection with you, is operating in alien territory, making contact with alien beings. We spend our entire lives doing this. And then you tell us that we can’t relate” – “[the autistic child] it’s a child, stranded in an alien world (...) a child requiring intensive on-the-job training in alien contact” (Sinclair 1993).

Philosopher Ian Hacking (2009b, 2010) has brilliantly explored these multiple uses of the alien metaphor in order to unveil how autism does not merely represent the object of science and media gaze but instead a subject that is producing knowledge. While fighting for the recognition of different ways to experience, perceive, communicate with the world and of understanding personal interaction and body language, autistic people are challenging the idea of normality and of “functional” human being. Indeed, every attempt to fix a supposed specificity of the human nature has always produced dehumanization, disqualification and rights exclusion. As the autistic self-movement, also parents use the Internet as an empowered space where to engage in autism awareness and advocate for their children’s rights. Both those groups use technology and virtual space as an example of a “technologically mediated agency” (Braidotti 2013) with the aim of spreading their political concerns, denouncing the exclusion produced by any kind of normative management of life as well as showing the different possibilities of being human as a way to sensitize the larger society to a broader sense of what it means to “be humans”.

Techno-devices as relational facilitators

Literature has supported the efficacy of virtual reality (Lahiri et al. 2015; Moore et al. 2005), social robots (Kim et al. 2013) and computer-assisted technologies (Ploog et al. 2013) as tools to enhance social, communicative, and language development of children with autism (Aresti-Bartolome and Garcia-Zapirain 2014). These new technologies - called ICTs (Information and Communication Technologies) - represent powerful teaching tools as allow students with special needs to “access tasks that would otherwise remain beyond their reach” (Drigas and Vlachou 2016:4). There are, for instance, specific software and apps called AAC (Augmentative and alternative communication) to use on mobile devices (such as iPad or Android tablets) targeted for autistic children in order to teach them how to recognize facial emotions (Lacava et al. 2007) as well as to improve existing speech or to replace non-verbal communication (Grynszpan et al. 2014). Other softwares, called PECS (Picture Exchange Communication Systems), allow autistic children with little or no communication to use pictures to communicate a request, the desired item, a thought, or anything that can reasonably be displayed or symbolized on a picture card. Images also translate into vocal inputs, encouraging a child to listen to the sentences he created and to begin to spontaneously use speech. Several studies indicate, for instance, that children with autism learn better with visual stimuli than with only auditory stimuli (Finkel and Williams 2002; Shabani et al. 2002; Vedora and Conant 2015). Overall, ICTs aim to help children understanding their environment,

improve their school performance and feelings of self-worth, increase their expressive communication and social interaction abilities as well as their so-called daily “functioning skills” such as attention, motivation, organization, self-help. Mobile devices and their related softwares and apps represent facilitators and enhancers, allowing autistic people to express their thoughts, needs, wants, and ideas.

Francisco is a huge fanatic of his tablet and he uses AAC applications both at home and at school. Pedro, his father, pointed out how “Francisco’s sensitivity to the touch, to images and colours, to lights and sounds” turned the tablet “extremely attractive” for him as well as a “great ally” in their relationship. They eventually learned how to communicate with each other and since Francisco is a nonverbal teenager, this avoids frustration and misunderstandings. In 2014, together with Irene and Zelia, I attended the panel “The promise of technology” run during the International Day of Disabled People (3rd of December), an annual observance promoted by the United Nations since 1992. The section opened with the speech of a distinguished Portuguese scholar Celia Sousa, who reported current barriers to technology’s access and use for disabled people as well as the scarcity of specific technology design, despite Portugal started fostered the use of ICTs in schools since 2008 and in six years it counted with already 25 ICTs centres throughout the country⁶⁵. Her complaint seemed even more severe considering that technology - as she argued in her closing statement - “is recognized as one of the central drivers of both school integration and social inclusion for people with disabilities and multinational technology companies have already open their market to users with different disabilities”. Irene took notes, commentated the meeting on her Facebook profile while simultaneously answered the questions of those parents belonging to the *Os Amantes de Saturno* group who could not attend. Zelia, on the contrary, seemed less impressed by the event, even if her restless hands eventually revealed a certain agitation. Encouraged by the informality of a coffee-break, Zelia eventually approached Prof. Celia, availing on - I thought - the great chance to discuss “offstage” some

⁶⁵ Here a brief chronology of the main Portuguese resolutions and institutions aimed at the digital inclusion of people with disabilities: 1999, INCNESI (*Iniciativa Nacional para os Cidadãos com Necessidades Especiais na Sociedade da Informação* - National Initiative for Citizens with Special Needs in the Information Society); 1999, the ACCESS Unit aimed at supporting the Ministry of Science and Technology (MCT) in the follow-up of INCNESI; 2004, Resolution n.1354 on digital inclusion; 2005, the Polytechnic Institute of Porto and Leiria created the NAID (*Núcleo de Apoio a Inclusão Digital* - Centre of Support to Digital Inclusion); 2006, Resolution n.120 - creation of an “Action Plan”; 2006, Convention on the Rights of Persons with Disabilities, Article 9, points G and H aimed at technology access for people with disabilities; 2007, UMIC, the ACCESS program signed 48 projects in collaboration with Engineering Centres for the use of technology for Rehabilitation and Accessibility (CERTIC-UTAI).

important issues with an expert. When she eventually re-joined Irene and me, her face was quite annoyed that I asked her the reason for her disappointment:

“they [technology experts] only speak about technical problems! They have to stop! we have a cultural problem here and it’s the most urgent...I mean the families can even know the importance of these tools, but then they keep their children at home because they know what’s the problem of our society, if inclusion was really comprehensive, we wouldn’t even need to talk about that [technical issues]!”

Indeed, Zelia brought the attention to the fact that stigma towards disability continues to pose an even greater challenge to the integration in society of people with disabilities and the understanding of their needs. During the second part of the section, other speakers presented different adapted toys⁶⁶ and several “autism-friendly” applications. For instance, Life is Game is a 3D game produced by the Oporto University and the University of Texas that by using real-time synthesis and automatic facial expression analysis aim at teaching children with autism to recognize facial emotions. After choosing an avatar - including humans, dolls and animals, children use their fingers on the touchscreen to draw the shape of key facial features such as eyebrows, eyelids, nostrils, and lips and capture virtual face’s emotional expressions. Similarly, in March 2014, the Faculty of Science of the University of Lisbon also created an informative platform about autism on Facebook called Enforcing Kids and a homonymous mobile app - released in 2015 through the App Android page of Google Play - that helps children with logic sequences.

Some of the parents I encountered in my fieldwork employ mobile applications with their children. During our informal meeting at a coffee, Laura showed me, for instance, those she uses with her son Oscar since he was 2-year-old. A voice reading application, which shows the words in the speech bubble and reads it aloud, offers to her an easier way to communicate with his son while stimulating him to improve his speech. With another app called “Grace”, she creates a “social story” or recreates specific contextual moments like breakfast by pairing photos of food (milk and cereals), people’s faces (her own and that of Oscar), places (kitchen) and objects (mug, spoon). Finally, a picture-based app allows Oscar to construct sentences by means of images and Laura eventually taught me how to use it. As she suggested we go for a

⁶⁶ For instance, todosemjogo.org is an adapted sports platform created by the Association of Cerebral Palsy of Almada Seixal (APCAS).

walk, she started scrolling through images, icons and photos in Oscar's iPad and eventually uploaded the photo of the park we were before. Then I selected this latter photo along with the image of a feminine avatar "walking", I wrote my name and finally added the photo of Oscar himself. Oscar enjoyed my proposal as he dressed up his denim jacket and gave me his hand.

Leonardo, the 13-year-old son of Rute, is learning how to use a keyboard as a learning support at school but also to improve the interaction with his mother. He prefers to write and visualize on a screen what he wants to talk about and to take his time to answer, which is possible insofar as his "visual" conversation exchange is slower than face to face verbal conversation. Another mother, Luisa is enthusiastic about a Windows Word supported symbol-based software called *Comunicar com Símbolos* (the Portuguese version of the English Symwriter) that visualizes the meaning of words while typing. She started using the program with her 6-year-old son Igor as soon as he enrolled in school. Thanks to her own experience, Luisa helps parents of the *Amantes de Saturno* group how to navigate the world of AAC apps. She offers her availability to chat with parents who have doubts or need advice, as happened with a mother worried of encouraging her child's "obsession" with technology and to somehow isolate him more than ever. Luisa, comprehensively answered: "technology segregates only when we as parents are not attentive, we have to manage the time our kids spend on their tablets and be always with them during the playtime, the tablet is just like the rest of the toys". She also suggests tutorials and shares what she learned. When I personally met up with her she gave me more details about her own experience:

"I hope that technology will make Igor more independent in the future because the results till now are good...but at first, it was hard to persuade her therapist because she said it was not worth to work with apps...but I am born stubborn! I installed the application, I uploaded some photos and recorded my voice...my son gained interest and began to use it and today he communicates with pictograms, he chooses what he wants to eat for breakfast, who he wants to play with, what he wants to see on YouTube, if he wants to go pee...he identifies the places where we go...I had a so great need to communicate with him! and he seems also happy to talk with me...I always say to parents 'Do not expect school or therapists to do everything!'"

Mobile devices as tablets represent attractive means for children with autism especially for some specific features they combine such as the rich colourful display and touch screen system. The AAC applications they supported help nonverbal children to make their intentions known and facilitate their interactions with other people. By means of these technological artefacts,

children, their relatives and therapists are learning how to mutually understand each other. In Portugal nor private health assurance plans neither public health system covers the cost of some apps as they are mainly considered recreational. However, some of the apps have basic-level that can be downloaded for free. The market is still small especially because the research that drives such apps is slow in achieving product development and release's stages.

Robotic technology is another innovative area associated with autism. Scholars have tested robots as tools to enhance social interaction skills in children with autism as well as to help them to decode body language and facial expressions (Pennisi et al. 2016). Research in robot-assisted autism therapy claim how these human-like techno-companions help children with autism to gradually enhance their attention toward “real” human beings and trigger their curiosity for social relations and improve their engagement (Kim et al. 2013; Scassellati, Henny Admoni, and Matarić 2012). Indeed, humanoid robots - which represent the most innovative outcomes of the SAR field (socially assistive robotics) - respond and react to social alike scenarios and are thought to help children exposing themselves and to learn how to not disappoint a “companion”, unlike an inanimate object such as a computer or a tablet. Beyond improving interaction, robots are also used to teach how to read feelings. Since facial expressions are extremely complex and difficult to be detected and understood by people with autism (Baron-Cohen, Golan, and Ashwin 2009; Sucksmith et al. 2013), scholars suggested that children are attracted to an android partner because of the predictability it provides and the clearness of its mechanical expression of emotions (Aresti-Bartolome and Garcia-Zapirain 2014; Sartorato, Przybylowski, and Sarko 2017).

In the *Os Amantes de Saturno* Facebook page, parents posted some news about a child-sized robot called Zeca (an acronym of the English expression Zeno Engaging Children with Autism), a project of the Portuguese venture “Robotics-Autism” of the University of Minho⁶⁷. The project started in 2009 in partnership with the APPAACDM (*Associação Portuguesa de Pais e Amigos do Cidadão com Deficiência Mental* - Portuguese Association of Parents and Friends of the Citizen with Intellectual Disability) and undergone an experimental study in 2014 with 45 school-age children aimed at studying new interactive ways with the humanoid robot. After the second trial in 2015, the project has been eventually presented (2016-2017) at schools, hospitals and psychology departments. Zeca shows five “universal” facial emotional expressions, that is it simulates feelings such as sadness, joy, anger, surprise and fear. This area of robotics

⁶⁷ (<http://robotica-autismo.dei.uminho.pt>)

presumes indeed that facial expressions regulate our daily conversations by providing relevant information about our interlocutor's intention and feeling, contributing to the construction of our emotional experience and interrelationship. Nevertheless, it is important to unmask the idea of the face as a universal corporeal vehicle for emotion's expression and as a result, as neutral blackboard where we can invariably read and interpret human emotions. Anthropology indeed has illustrated how emotions expression and understanding mutually rely on social settings, cultural actors and precise situations, composing together the cultural and social ecology of emotions (Maclaren 2014; Rosaldo 1984).

Dwelling in technological otherness

So far, I explored how a techno-companion such as the Internet represents a tool through which people with so-called HFA could speak for themselves and shape new ways of considering autistic people. I also illustrated, by referring to my own fieldwork, how children with autism and learning and communication difficulties use technology as an assistive tool in order to improve their relational and communication skills. However, beyond this "functional" use, people with autism experience an intimate form of inter-dependence with the technological otherness. The ethnographic accounts I reported illustrate that technological companions have a profound impact on the agency of children with autism insofar as they are enhancing their possibilities of expression and relation (Marks and Milne 2008). I argue thus that technological devices belong to a class of artefacts experienced as means through which one's environment is encountered, perceived and acted on. The philosopher Don Ihde (1990, 2002) has defined the relations between human beings and such artefacts as "embodiment relations", since these technological objects are capable of engaging in "symbiotic" relationships with the human body (Brey 2000). By taking into consideration the boundaries between us, as practitioners, the tools we are using, our body and the environment, Michael Polanyi (1958) also suggested that the learning process of becoming skilful practitioners can be regarded as the act of making tools part of our own body, insofar as while using them:

"we shift outwards the points at which we make contact with the things that we observe as objects outside ourselves (...) these are not handled as external objects (...) they remain necessarily on our side of it, forming part of ourselves, the operating persons. We pour ourselves out into them and assimilate them as parts of our own existence. We accept them existentially by dwelling in them" (idem:61).

Thanks to their intersecting relationship with humans, artefacts assume a social value and meaning depending on the use and context in which they are positioned (Appadurai 1988). Moreover, technological objects like mobile devices represent also social companions or “actants” (Latour 2007) because despite lacking human intentionality as other non-human objects they have nevertheless the capacity to act into a network of interactions with human partners. As my ethnography explored, technological artefacts assume also a semiotic value insofar as they help people to model their own subjectivity and to produce a meaningful understanding of the self and of the other. Indeed, the use of tech-devices gives rise to particular ways of embodying and managing new practices of knowing and expressing of the self. Moreover, technology represents a lens that, by revealing the different ways in which children with intellectual disabilities can deploy their human agency, shows the limit of the human as a coherent and universal category. Following these arguments, I claim that the embodiment relation between people with autism and technology (as a non-human otherness) represents a good example for anthropologically and critically question any normative idea of the “human”, an issue I will explore in the next section.

From a human to a dis/human condition of being

In this section, my purpose is to explore how people with autism, by showing their different ways of approaching and understanding the surrounding environment, challenge our humanistic traditional idea of what is inherently human. In order to develop this argument, I will first trace the ways in which the scientific discourse has described autistic people as incomplete or unfulfilled human beings, as more animal-robot look-alike than human-like. In this way, I will show how people with autism have been marginalised on the boundary of “human being-ness” as they are supposedly lacking the very qualities of “the human”. I will argue that this view of autism as an extreme form of otherness originates from Humanism’s restricted and narrow notion of what counts as human, which provided the normative touchstone for guiding and measuring human normality, rationality, and ability. In addressing this issue, I will mention and primarily rely upon Braidotti’s critical post-humanism (2013) and on her call for productive alternatives that might emerge in response to the oppressive nature of an ideal of human, for which indeed any non-conforming group or person becomes synonymous with inferiority and subordination, giving rise to forms of exclusion and disqualification. Following Braidotti’s call for looking forward for an extension of the kinds of (post)human we are already in the process of becoming, I will take the work of some critical disability scholars who have re-imagined “disability” in post-human times. I will eventually argue how people with autism as non-normative bodies

represent “detonating subjectivities” able to force us to critically think against a universalist understanding of the individual and to re-imagine our ways to look at intellectual disability.

Less than human

As I showed earlier in this chapter, autistic people have employed the metaphor of the alien to apprise us about how they perceive themselves in a neurotypical world, an issue that Ian Hacking (1991, 2009b, 2010) has extensively explored. Similarly, because of their peculiar ways of experiencing the environment and their supposed own world (exemplified by the image of the “withdrawn autistic child”), they have also been described as “other” than human beings. Since its first appearance indeed autism lies for a condition affecting core human requisites, such as social interaction and language. Asperger and Kanner, for instance, described the “autistic condition” through a wide set of “typical” traits and behaviours that are very different from those expected from a typical child (Lyons and Fitzgerald 2007; Wing 1997). Novels, TV-series, movies or autobiographies have also contributed to a considerable “proliferation of autism stereotypes” (Draaisma 2009:1476) and to reinforce the use of some appellatives - such as the autistic savant, geek or robot-alike - to sum up the way in which autistic people’s different brain is supposed to work. These fashioned and stereotyped clichés situate people with autism in a world that is thought as extremely obscure and irretrievably distant from us. As Loftis (2015) summarizes:

since our society commonly imagines the mind as the symbol of what separates us from animals and depict cognitive functions as the very thing that makes us humans, those with cognitive disabilities and differences are frequently depicted as less than human. This has led to the popularity of tropes that associate autistics with aliens and robots - both figures are represented as lacking qualities (emotion, feeling) that make for a complete human. The autistic mind is commonly compared to a machine or computer, metaphors that again suggest a less-than-human quality to those with cognitive differences (idem:17).

The last DSM (American Psychiatric Association 2013) still describe the conditions or behaviours that should appear to satisfy autism criteria by employing a “deficit” or “lack-based” lexicon. Children should display speech-language and relational impairments - “by responding inappropriately in conversations, misreading nonverbal interactions, or having difficulty building friendships appropriate to their age”, and also repetitive behaviours - “they are overly dependent on routines, highly sensitive to changes in their environment, or intensely focused

on inappropriate items”. Adjectives such as delayed, stereotyped, repetitive, restricted and non-functional describe the behaviour of a child with autism as if her specifically human qualities were missing, damaged or inadequate. Even after the widening of diagnostic criteria and the inclusion of Asperger disorder into the autism spectrum, a person with autism is always lacking something or on the contrary expressing an excess. Compared with typically developing children, children with autism show to have something less or something more or at least something bizarre or puzzling to be solved.

Psychiatry identifies autism spectrum as a heterogeneous set of neurodevelopmental disorders characterized by deficits in social communication and reciprocal interactions as well as stereotypic behaviours. Autism is thus individualized by describing its lacking, disabling and non-conforming traits. For these reasons, people with autism might find themselves with unequal access to education, under-employed, unemployed, or excluded from housing, leisure, politics, transportation, services, and other support systems. Moreover, although a single factor has not yet been identified, one of the largest advancements in understanding the aetiology of ASDs is the identification of a variety of genetic and neurophysiological variations, meaning that autism is thought as inscribed in the body (genes/brain). This analogy is nothing but a dispositive of identity construction that assimilates the fact of having a neurodevelopmental disorder such as autism to an inherent incapacity to perform a normative subjectivity. Indeed, the behaviours of people with autism are often labelled with adjectives such as disordered or unfunctional and people themselves are often described as non-fully human beings. Neurobiology and genetics presume that human beings, beyond being influenced by their cultural and social settings, can also bodily sense and approach the world in different ways (Jaarsma and Welin 2012). Science can use the supposed neurophysiological variations of autistic people’s brain as evidence of their “naturally grounded” antisocial behaviour. Moreover, individuals diagnosed with ASDs are estimated to have a high prevalence of even profound intellectual disabilities (Bryson et al. 2008; Matson and Shoemaker 2009; McKenzie et al. 2016). According to the DSM 5 individuals with intellectual disability - formerly referred to as “mental retardation”⁶⁸ - have difficulties with aspects of mental capacities such as understanding, reasoning, abstract thought, problem-solving, exercise judgment and language use effectively and with adaptive functioning, which refers to the skills needed to live in an

⁶⁸ Following the publication of the DSM-5 in 2013, the official classification changed from mental retardation (MR) to intellectual disability (ID).

independent and responsible manner, including communication, social skills, and self-help skills (for example, getting dressed, feeding, ask for help, manage money). There seem to be rational aims that must be fulfilled for a life to be a good life. Indeed, the lack of self-consciousness and of the language itself preclude these people self-determination and the ability to express or represent the self.

Gernsbacher (2007), for instance, denounced how psychology has dehumanized autistic people because of their supposed lack of intentionality and cultural learning. She further argued how, within all history of psychiatry and psychology, the scientific discourse legitimates the portrayal of people who do not meet the normative requirements of a society as different and morally deviant humans. As a result, people with autism have been described as “less-than-human” beings or as having less than a whole body insofar as their diversity is conceived as affecting the possibility to be a full and functional human individual. In other words, by relying on their power to ascribe people defective characteristics, scientists have “employed” autism as a counterexample to the traits defining humanity. For instance, cognitive scientist Pinker (2002) placed autistic people together with robots and chimpanzees. The three do not show evidence of cultural learning - “a uniquely human form of social learning that allows for a fidelity of transition of behaviours and information among conspecifics” - and their mind is unequipped “to discern other people’s beliefs and intentions” and “incapable of the kind of learning that perpetuates culture. (...) Together with robots and chimpanzees - concludes the author - people with autism remind us that cultural learning is possible only because neurologically normal people have innate equipment to accomplish it” (idem:62).

The psychologist Bryna Siegel, author of *The World of the Autistic Child* and director of the Autism Clinic of San Francisco stated that autistic people “do not understand or are missing a core aspect of what it is to be human” (Falcon and Shoop 2002). Similarly, Clements (2005) reported in his book “People with autism behaving badly” that autistic children are “still considered more animals than people, perhaps some missing link in the chain of evolution” (idem:200). According to neuroscientists Ramachandran and Oberman (2006), “at first glance, you might not notice anything odd on meeting a young boy with autism. But if you try to talk to him, it will quickly become obvious that something is seriously wrong (...) autistic children are not able to function normally” (idem:63). In their article “Broken mirrors: a theory of autism” they speculated, indeed, about a potential treatment aimed at restoring autistic children’s “broken mirror neurons system” - allegedly considered the neurophysiological layer

involved of imitation and social interaction - so to solve children's isolation and lack of empathy. In this regard, those among the autism associations that disagree with the neurodiversity claims support the idea of autistic people as incomplete or damaged people. Cure Autism Now, for instance, welcomes neuropharmacology and support the development of prenatal genetic testing as means to "cure" autism, reiterating the idea of "bodily functionality" as a condition to be fully human. In the same way, the recovery narratives collected on their YouTube channel implicitly suggest the idea of a child with autism as waiting to "regain" her (supposedly lost) humanity.

The assumption of a unique way of being human leads to the misunderstanding that those who differ from the normative model or unfit its expectations are missing something. Virtually, for every supposed human inherent quality that is missed, there is deviant human, a dis-human. What autism is missing or "misfitting" is the ability to speak and to socially interact with others as well as the intentionality and self-consciousness. Moreover, these deficits in autism are supposed to be inscribed in the body. Autism, indeed, is a neurodevelopmental disorder, meaning that at the heart of the autistic person's social un-functionality there is a "biological" or "neuronal" defectiveness. As a result, the understanding of the social in autism is individualised, insofar as it becomes a property of the individual. In other words, the ability to socially interact is something that a person is or has inherently or naturally into the body. In a certain way, the idea of a "neurological substratum" of social skills has fabricated autism as a failure (or an exception) of human normal sociality. When autism matches with an intellectual/learning/developmental disability (all terms used in psychological and medical contexts to refer to cognitive impairments), the failed ideal corresponds to the narrow and exclusive conception of the human being as able of self-consciousness and rational thought. Is, thus, "the human" a still good notion for thinking about autism?

In the collective introduction to the American Ethnologist column "Vital Topics Forum" dedicated to "On Nature and the Human", Fuentes (2010) argued how since its beginnings "one powerful contribution of anthropological work has been to challenge any unitary theory of the human" (idem:512). In his contribution to the column, Ingold brilliantly proposes to look at what people *do*, how they live and relate as the remedy of any theoretical attempt to define what people *are*:

[t]he recognition of the human is the product of what Giorgio Agamben calls an “anthropological machine” that relentlessly drives us apart, in our capacity for self-knowledge, from the continuum of organic life within which our existence is encompassed. This machine drives the project of Western thought and science. Not only does it generate the problematic of the universal and the particular, of sameness and difference, but it also ensures that it will never be resolved. To escape the impasse (...) requires us to dismantle the machine. The first step is to think of humans in terms not of what they are but of what they do (...) Humanity does not come with the territory, from the mere fact of species membership or from having been born into a particular culture or society. It is rather something we have continually to work at. What we are, or what we can be, does not come ready made. We have, perpetually and neverendingly, to be making ourselves. That is what life is, what history is, and what it means to be human. To inquire into human life is thus to explore the conditions of possibility in a world peopled by beings whose identities are established, in the first place, not by received species- or culture-specific attributes but by relational accomplishment. Unlike the incongruous hybrids of biology and culture created by the anthropological machine, real-world humans build themselves, and one another, in the crucible of their common life (idem:514).

Given these considerations, in what follows, I will refer to the critical post-humanism approach of the feminist philosopher Rosi Braidotti as well as to critical disability studies because of their insightful contribution on critical thinking about what we think that lies at the core of humanity and who we include in. Both approaches represent contemporary valuable engaged approaches committed to revealing all kind of oppression and objectification involved in the social and political process of “human” identity construction.

Towards a post-human condition of being

As Braidotti (2013) points out, the roots of the ideal Man of humanism go back to the Greek sophist Protagoras’s assertion that “man is the measure of all things”, a notion later reclaimed and reinforced by the Italian Renaissance with the Leonardo da Vinci’s iconic graphic figure, and emblem of Humanism, of the “Vitruvian Man”, the ideal of bodily perfection (idem:13). She further notes that in the course of history “humanity” always represents “very much a male of the species: it is a he. (...) he is white, European, handsome and able-bodied” (idem:24), “implicitly assumed to be masculine, white, urbanized, speaking a standard language, heterosexually inscribed in a reproductive unit and a full citizen of a recognised polity” (idem:65), “a rational animal endowed with language” (idem:141). This authoritative humanist

ideal is one that people rarely match up to. Indeed, according to this definition not all of us can say that we have always been human (or that we are only that).

Historically, this humanist ideal developed into a hegemonic and cultural “civilizational model which shaped a certain idea of Europe”, a mutation canonized by Hegel’s dialectics (idem:14), according to which history relies on a contradictory process between opposing sides that leads to a linear evolution from less sophisticated to more sophisticated forms:

“This Eurocentric paradigm implies the dialectic of the self and the other, and the binary logic of identity and otherness as respectively the motor for and the cultural logic of universal Humanism. Central to this universalistic posture and its binary logic is the notion of “difference” as pejoration. Subjectivity is equated with consciousness, universal rationality and self-regulating ethical behaviour, whereas Otherness is defined as its negative and specular counterpart. In so far as difference spells inferiority, it acquires both essentialist and lethal connotation for people who get branded as “others”. These are the sexualized, racialized, and naturalized others, who are reduced to the less than human status of disposable bodies” (idem:15)

Therefore, humanism sets standards for individuals’ perfectibility and also for their cultures and created the social, discursive and spiritual values at the basis of the Eurocentric and Imperialist policies of the 18th and 19th century in Europe. This tendency to othering, that is any action by which an individual or group becomes classified as “not one of us”, charged humanism of banishing many others who cannot fit in its rigid fold. Whilst this view justifies, for instance, the violence of colonial policies, it has also represented the source of hope and aspiration for the freedom and independence on the part of oppressed peoples, a quality that Braidotti thought as responsible for Humanism’s longevity (idem:16). Humanism has supported liberal notions of autonomy, self-determination, responsibility but also gave us many emancipatory contributions, such as universal human rights, equality, social justice, legal systems and trans-national declarations respecting and protecting these rights. Only after the II World War throughout the 1960s and 1970s, “an activist brand of Anti-Humanism”, formed among others by feminism, decolonization and anti-racism, anti-nuclear, and pacifist movements, radically questioned the Humanist ideal and disclosed the complicity between the philosophical ratio of the humanistic universalism and the real-life social practices of injustice. But it is Foucault’s *The Order of Things* that represents the “ground-breaking critique of

Humanism” at it questioned for the first time the very idea of “the human” and formalized its epistemological and moral crisis by announcing the “death of the Man”:

The Vitruvian ideal Man was literally pulled down from his pedestal and deconstructed. [it] constituted, in fact, the core of a liberal individualistic view of the subject, which defined perfectibility in terms of autonomy and self-determination. (...) It turned out that this Man, far from being the canon of perfect proportions, spelling out a universalistic ideal that by now has reached the status of a natural law, was, in fact, a historical construct and as such contingent as to values and locations (idem:24)

Braidotti aligns, indeed, with post-structuralist thinkers, such as Derrida, who called for insubordination from the idea of an intrinsic and universalistic idea of “human nature”, as well as with feminists philosophers, like Irigaray, Kristeva and Butler, and anti-colonial thinkers, like Fanon and Shiva, who rejected and questioned the abstract ideal of Man as a symbol of the white, European, able-bodied male by destabilizing the “humanist man” and with it the very moorings of modernist philosophy and politics. Braidotti’s critical post-humanism “marks the end of the opposition between Humanism and anti-humanism and traces a different discursive framework, looking more affirmatively towards new alternatives” (idem:37). The author indeed suggests focusing on new ways of understanding the human subject and eventually develop “affirmative perspectives on the posthuman subject” rather than identifying the hopelessness of humanism or further enforcing the binary differences between humanism and anti-humanism (idem:45).

Her call for post-human thinking means not only shifting how we understand the human but also rethinking our relationships with our “other neighbours”, namely our environments and its human and nonhuman inhabitants, within our current globalized and “technologically mediated societies” which involve debates, developments and controversies in relation to “robotics, prosthetic technologies, neuroscience and bio-genetic capital” (idem:2). Indeed, nowadays we already experience a “posthuman condition [that] urges us to think critically and creatively about who and what we are actually in the process of becoming” (idem:12). A posthuman theory of the subjective, therefore, emerges as “an empirical project that aims at experimenting with what contemporary, biotechnologically mediated bodies are capable of doing” (idem:61). Braidotti proposes to decentre individualism and overcome an anthropocentric worldview and she eventually argues for an alternative “*zoe*-centric worldview”, namely a view that

emphasizes on *zoe*, the “dynamic, self-organizing structure of life itself” (idem:60). *Zoe* represents the life-force, the property of the monolithic universe of matter and not of an individual or species. For the author, to put *zoe* at the centre outlines a three-phase process, which she labels “becoming-animal, becoming-earth and becoming-machine” (idem:66).

I will particularly mention the third process, as it is particularly crucial in my field. In this regard, the machine can no longer be understood as a metaphor for humanity or something completely others to people. Inspired by Deleuze and Guattari’s notion of assemblage, Braidotti advocates a model of becoming-machine that lie and consider the “playful and pleasure-prone relationship to technology that is not based on functionalism” (idem:91). The playful and mutually beneficial relationship between human and machine, then, is reimaged not as a relationship between product and consumer, but as two distinct and nonhierarchically ordered species. This technologically mediated relationship allows us to think of ourselves as “bodies without organs”, that is, without a teleological defined efficiency. Rather, the posthuman subject is able to account for the increasingly technologically-mediated environment in a manner that is experimental and not exclusively profit-driven.

Under those circumstances, autism and intellectual disability represent, in many senses, quintessential post-human conditions as they show the importance for their existence of the interdependence and mutual connections with other humans as well as non-human entities such as technologies. They show, in an extreme way, the fictional and abstract character of the autonomous and self-sufficient human. The daily intertwining relationship that people with autism interlace with non-human others, such as techno-devices, are subtle and complex in both interactional and therapeutic contexts. In Braidotti’s terms, there is a multi-species relationship between them. Despite I have especially focused on techno-companions, I could report also an episode showing the relation with non-human bodies such as mere objects. I remember, for instance, when at the park Oscar was experiencing the texture of a pebble with his face and then he started touching my arm with it as peculiar ways to approach me. Oscar was showing me that everyone has specific bodily reactions and ways of approaching the materiality of other’s presence, conveying a different sense of the perceptual relationship with the surrounding environment. Similarly, Dawn Prince-Hughes (2004), a mother and anthropologist diagnosed with autism, with her work *Songs of the Gorilla Nation* or the autistic-star Temple Grandin’s work (1995) on cows’ management illustrated autistics people’s relationship with non-human others such as animals.

The dis/human politics

Exclusion and disqualification are two forms of the epistemic violence of humanism that reduce others to the non-human or sub-human status. As Braidotti notes, humanism “is a constitutive source of ignorance, falsity and bad consciousness for the dominant subject who is responsible for their epistemic as well as social dehumanization” (Braidotti 2013:28) and further underlined how the humanist subject defends himself through the opposition to “the sexualised, racialised and naturalised others that occupied the slot of devalued difference” (idem: 144). Because of their being “unfit” to some normative categories (i.e. gender, culture, social class, sexual orientation or way of living), people can experience different forms of disqualification and social exclusion. The Other, as a logical deviance and counterpart of any normative construct, becomes the target of many forms of violence such as objectification, oppression, and even deprivation of liberty. Feminism, gender and queer studies, and critical race studies shown, for instance, how hetero/sexism and racism has marginalised and discriminated gay and queer people as well as women and black people for being non-conforming and minority identities. Likewise, the concern of disability studies for the discriminatory, oppressive or abusive behaviour and practices arising from the belief that disabled people are inferior to “normal” others is not new. At this regard, disability scholars have addressed the violence of *disablism* - a term referred to “a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being” (Thomas 2007:73) - and unveil the role of institutions, culture and social relationships in its constitution (Goodley and Runswick-Cole 2011). Titchkosky (2012) also observed how disability studies have explored “how certain people are regarded as on the edge of all that counts as human” and studies how the exclusion of from ordinary activities, such as education, work, leisure, and love, is normalized:

Disability-exclusion is normalized through an array of cultural processes that make “disability” represent limit without possibility. Disability is made to serve as a signifier of an end without appreciable difference and without future (...) Blindness, for example, is not imagined as way to perceive differently but, instead, as “not seeing”; wheelchair use is typically regarded as “confinement,” not as moving differently; and differences in learning and emotions are imagined as an inability to think, learn, remember, or as a lack of control, as unpredictability. Within Western cultures, disability is typically taken for granted as the end of an expected form of functionality, voided of normalcy, and transposed into the end of human legitimacy. Such an

interpretive process easily gives way, both figuratively and literally, to treating disability as a stage par excellence for end-of-life dramas and debates (idem:82).

Despite humanist efforts to establish a universal sense of humanity and of the human embodiment, not all bodies grant the status of persons because of their disabilities. Indeed, the idea of an independent, autonomous and self-conscious subject, which comes to mind when we evoke the human ideal has also led to the institutionalization of disabled people as well as to their exclusion from social and civil rights. Disability indeed has a distinctive quality and role in problematizing the human as “it is a category anyone might enter in a heartbeat, challenging lifelong presumptions of stable identities and normativity” (Fuentes et al. 2010:517). Furthering this quality, critical disability studies (CDS) have positively embraced Braidotti’s notion of post-human insofar as “disability has always contravened the traditional classical humanist conception of what it means to be human” (Goodley, Lawthom, and Runswick Cole 2014:342). Moreover, understanding the human through disability is crucial to comprehend and critically consider the kinds of humans currently valued in society as well as to realise how people leave at the edge of humanity such as disabled people - and among these especially people with learning disabilities - actually live in contemporary society (Goodley and Runswick-Cole 2014). The interest in thinking about the human and its relationship with the disability is indeed political, insofar as it reveals how medicalisation and pathologisation represent the similar colonising tendency of the disabled Other, understood and described in terms of what it is not or is not able to do.

Braidotti forecast the importance of disability for a posthuman project as she argued how “ever mindful that we do not yet know what a body can do, disability studies combine the critique of normative bodily models with the advocacy of new, creative models of embodiment” (Braidotti 2013:146). Confronted with the disability, the unitary, rational, independent, able-bodied human subject reveals itself as the fiction that it really is. Disability indeed upsets and subverts the function that Braidotti ascribes to the human, insofar as it operates as “a normative convention, which does not make it inherently negative, just highly regulatory and hence instrumental to practices of exclusion and discrimination (idem:26). This operability of the human as a norm that stands for “normality, normalcy and normativity” is exemplary when we look at the ways in which the educational systems organized its practices around the idea of a “normal” cognitive development and progress of social abilities for a child. For instance, social skills training programs for children with autism focus on “synchronize” (so, normalize) them

with developmental, linguistic, and social norms. However, these norms have not been critically evaluated, so that these therapeutical programs fall to recognize participants' existing social abilities and accomplishments and do not consider or support "autistic ways" of learning and being social. A post-human critical thinking about disability assimilates the refuse of any form of universalism with regard to a quality or essence about "human nature". Furthermore, it agrees with the consideration that humans are not individualised entities, but subjectivities firmly interconnected with non-human subjects, tied into and caught up in the ever-growing whirlpool of technology and communication that shift us through real and virtual places and contexts. As well as Braidotti recognized the emancipatory contributions of humanism, also critical disability studies acknowledge disability movement's claims which are accordant to normative human values and rights. In particular disability scholars argued that while

“disabled people have historically been excluded from the category of the human, [they] continue to demand inclusion into this category. Hence, we are not suggesting (...) to give up on the functional utility of human rights nor the social justice of liberal principles of equality in our fight to challenge disablism (Goodley et al. 2014:344)

For instance, as I described in Chapter III, families are fighting for their disabled children to be recognised on a day-to-day basis as humans with the same rights. Parents' practices are crucial because they ask us to think again about the kinds of human beings we are and the kinds of humans we value, accept, include and permit to thrive. Furthermore, through the everyday negotiations, fights, lobbying and debates they enacted inside their communities, parents call for and rely on anti-discriminatory legislation, disabled people's convention of human rights as well as educational and work policies in order to achieve their children's community inclusion. And in doing this, they appeal to the humanness of their children. Following parents' narratives and experiences, it became urgent to acknowledge the human claimed in the lives of autistic people with learning disabilities and at the same time to remain very critical of it insofar as it perpetuates a humanist view narrow and discriminatory. Goodley and Runswick-Cole (2014) describe this (apparent) contradictory reality as "dis/human" since they contend it

“simultaneously acknowledges the possibilities offered by disability to trouble, reshape and re-fashion traditional conceptions of the human (to 'dis' typical understandings of personhood) while simultaneously asserting disabled people's humanity (to assert normative, often traditional, understandings of personhood)” (idem:2)

Indeed, in advocacy, we often hear self-advocates, as well as parents, say that people with autism have the same rights to a home, a family, a job while claiming that to treat them equally means also to acknowledge their difference. Policy struggles to recognize these tensions and to understand the dis/human as it is informed by a notion of the human as a rational, independent individual self.

Like I mentioned earlier, the therapeutic approaches that aim at enabling children with autism and learning disabilities to become active and “functional” members of their community emphasize the “normative” aspect of the idea of the human. Hence, they did not pay attention to the dis/human position of disability. If we interrogate and questioned the supposed qualities and abilities of the so-called “normally developed” child, we find out that children with autism are not “failed versions” of human beings, but instead post-human subjects whose humanity has been questioned and humanistic ideals denied. In this light, autistic people, like other disabled people, represent one of the largest disenfranchised minorities in the world. We should evolve from a society that by merely using the lens of pathology can only see people with autism as a checklist of deficits, dysfunctions, and actions that they cannot do or struggle with to a society that appreciates and respect autistic people for their own distinctive strengths and attributes. This is possible though, only if we parallel this epistemological view with the provision of appropriate accommodations, supports, resources and research to improve the quality of life for autistic people and their families.

In this regard, during one of our online chatting about the ultimate aim of technology’s use by children with autism Luisa pointed out:

we need to move beyond the social façade of autism awareness to appreciate our children, I mean appreciate them in their fullness (...) that’s why the real power and successfulness of technology lies in that it could help society to recognize the potential and value of children with autism and challenge its idea of normality

To embrace people with autism’s different humanity, especially those with intellectual disability, means to challenge ourselves and not merely to exceptionally admit their presence in our workplaces, classrooms and communities just as a compassionate gesture. It’s about to ensure them as already members of our society the greatest chances for their well-being.

Non-normative bodily presences as “detonating” subjectivities

Insofar as they keep thinking people with autism as merely disabled/impaired/unfunctional and then non-fully human beings, both psychiatric and media lexicon provide the semiotic conditions supporting the preservation of a group of socially and politically “excluded others”. As discussed before, feminist critical post-humanism and critical disability studies represent two promising approaches that aim at denying the idea of an exhaustive human nature and at reading human diversity as a project. For instance, these approaches taught me how to be more attentive to the bodily practices of people with autism, especially those tied to their “symbiotic” interactions with humans and non-humans companions. These relationships, which I respectively addressed in Chapter III and in the first section of this chapter, show the disobedience of people with autism in being merely understood through the category of disordered bodies or by the liberal and capitalist “functional model” of the body. In what concern this section, I explored the multiple imbricated relations between autism and the current techno-media landscape to show how the forms of agency provided by technological devices represent an example that urges us to rethink the human as a definite category. Indeed, the impact of these non-human companions on children’s embodiment and subjectivity raises fundamental questions about the malleability and variability of humanness, of people’s ways of living, of relating to each other and of sensing the environment. In other words, insofar as it is actively included in a plot of intersubjective relations, the technology could represent a means through which critically acknowledge the transformative paths of human beings in contemporary society.

My fieldwork shows how technology contributes to shaping autistic children’s experience of the self and of their surrounding human and non-human environment and the need thus to epistemologically reconsider technological artefacts not merely as instruments but rather as companions in people’s subjectivity’s construction and transformation. In our technologically mediated society, human and non-human mutual relationships are inevitable and urge us to acknowledge their ability to produce new subjectivities. Similarly, these intra-species relations force us to question the moral values through which we think disability, namely to repudiate the idea that a subject diagnosed with a cognitive disability is necessarily doomed to exclusion and disqualification because of her supposed social deviance. At this regard, anthropology reveals how the body is the experiential lieu where the subject constructs her own new ways and meanings of living a meaningful life. By condemning body’s reduction to its supposed lacking “social functions”, a posthuman vision about disability is thus productive and

affirmative. Following Braidotti (2013), because of being marginalized subjectivities disabled people benefit from a decentralized position from where they are able to deconstruct the normative discourse about their “defective” or “deficient” body. Considering my fieldwork thus, I acknowledge that as marginalized subjects, autistic people own the quality of being *detonating* subjectivities, meaning that they represent situated bodily subjectivities whose experience push us to “detonate” our epistemological perspectives on the human so to broaden our idea of the human by embracing its plurality of possibilities.

People with autism incorporates a “disruptive potential” as they force us to critically look and reconceptualise our thinking on bodies and non-normative subjectivities. I think, indeed, that a critical anthropology aiming at engaging with the issue of citizenship and intellectual disability, should confront itself with the power relationships that lie in the construction of autism as an identity as well as attempt to theoretically and politically contribute for a broader notion of personhood and humanity. As an anthropologist, my contribution is to critically acknowledge parents’ will to unveil social and political implications of living with people with autism and cognitive disability as well as to enlarge our citizenship practices in such a way as to acknowledge different subjectivities, their humaneness, and their different ways to inhabit the world and our relationships. Nowadays, indeed, people whose bodies are not recognized as rightful to take part in society are denied of a place for citizenship and it is up to us to envision a new political space in which we can eventually co-habit as equally different humans.

A call for citizenship

Philosophy and political thinkers conceive the ability to reason as the mark of the humanity and thereby extend only to humans the rights of equality, dignity, justice, and citizenship. Autism makes a very interesting case study for exploring our ethical and political thinking towards intellectual disability and citizenship. For instance, since they supposedly lack a theory of mind - that is, the ability to attribute and recognized beliefs, intents, desires, pretending, emotions to others - people with autism seem to have no conception of moral duties or concerns towards others nor feelings of reciprocity, affectionate regard or sense of belonging. Moreover, those autistic people showing also cognitive impairments are assumed to do not have self-consciousness nor practical reason: as “failed” moral agents “unable” to respond with appropriate social behaviours, they are altogether lacking the capacity for citizenship. In this last section, I will explore the growing body of recent work that tackled intellectual disability and citizenship (Barnbaum 2008; Kittay and Carlson 2010; Nussbaum 2006; Rogers 2013;

Simplican 2015; Wong 2009) in order to acknowledge how their legacy contributed to denounce the depriving of rights of people with mental disabilities and to question the normative ideal of citizenship when it comes to people with cognitive impairment. Then, I will finally report parent's claims for the recognition of a broader sense of citizenship able to include people with cognitive disabilities as well as their call for a more engaged sense of our own citizenship in engagement with disability rights.

Sociality, citizenship and intellectual disability

As I described in the previous section, a narrow understanding of the human led to the discrimination and exclusion of those people considered under the threshold of its normative features. Also debates over the meaning and nature of “the social” reveal the normative conceptions about the accepted ways to live in society and influence the claims about the nature of citizenship. For instance, Hollin (2014) has brilliantly investigated how a re-conceptualization of the social as a result of a dominant role of cognitive theories in psychology during the 1980s makes autism a “social disorder”. From a few decades, the fields of cognitive science, genetics and neuroscience became increasingly central in discourses around human nature and subjectivity. Pálsson (2007), for instance, argued how biomedical scientific advances, beyond to further our understanding of disease and body, have changed our self-understanding and perception of what it means to be human. New genetics, in particular, have redefined our notions of citizenship, social relations, family and identity (idem:3). This body of knowledge and technologies has indeed an impact upon the way we think about ourselves and resulted in new articulations of the notions of sociality and citizenship⁶⁹ (Novas and Gibbon 2008), showing how these represent a transforming and open-ended corpus of features and patterns, continuously affecting people's lives and representations.

At this regard, while autistic self-advocates, namely people with so-called high-functioning or formerly Asperger syndrome, have positively claimed their cognitive diversity as a form of counter-identity, people with so-called low-functioning autism often exhibit comorbid conditions such as cognitive delay and impairments. One of their distinctiveness concerns

⁶⁹ Rabinow (1996), for instance, explored how genomics knowledge led to the emergence of a “bio-socialities”, that is the creation of new identities and groupings cohered around genetic/biological conditions. Rose and Novas (2005) showed how people rely on genetics or neurological features also to claim citizenship, giving rise to forms of “biochemical citizenship”. Young (2012) investigated how neuro-imaging technology affected notions of the social by entailing a conception of the “social brain”, a brain organized around three interconnected “functions” (mind-reading, empathy, and self-consciousness) and specialized for social interaction.

indeed cognitive ability, insofar as while the former show differences in perspective or information processing styles, the last are supposed to show an underdeveloped intellectual functioning. Nevertheless, people with autism show altogether a “misfitting” sociality. Garland-Thompson (2011) proposes the term “misfit” as a critical keyword that aims at reframing dominant understandings of disability. While the term “fit” denotes a harmonious encounter, the term “misfit” conversely describes an incongruent relationship due to contextual variables:

the problem with a misfit, then, inheres not in either of the two things but rather in their juxtaposition, the awkward attempt to fit them together. When the spatial and temporal context shifts, so does the fit, and with it meanings and consequences. Misfit emphasizes context over essence, relation over isolation, mediation over origination. Misfits are inherently unstable rather than fixed, yet they are very real because they are material rather than linguistic constructions. The discrepancy between body and world, between that which is expected and that which is, produces fits and misfits. The utility of the concept of misfit is that it definitively lodges injustice and discrimination in the materiality of the world more than in social attitudes or representational practices, even while it recognizes their mutually constituting entanglement (idem:592-93).

By giving attention to the varying of contexts and its related lived embodiments, the notion of misfit avoids any generic notion of an “asocial” body that silenced the social and political barriers that actually disable it and highlights instead the “adaptability, resourcefulness, and subjugated knowledge as potential effects of misfitting” (idem: 592). Similarly, Ochs and Solomon (2010) introduced the notion of “autistic sociality” to discuss its implications for an anthropological understanding of sociality. If human sociality consists of a range of possibilities for social interactions influenced by the dynamics of individuals and social groups, then autistic sociality is one of these possible forms of coordination. A rethinking of autism as a condition that compromises sociality is particularly urgent in our times. Insofar as our contemporary high-competitive society is increasingly promoting certain neoliberal aspects of subjectivity, such as responsibility, self-promotion, and independence, autism is further challenging our anxiety about precariousness and unemployment. People with autism disrupts, indeed, the logic of the self as the site *par excellence* where to negotiate social expectations of (re-)productivity whether in the workplace, through the kinship system, or with regard to *autopoiesis* practices such as self-investment. As a group whose identity is based on difficulties conforming to social

norms, autistic people are likely targets for social discrimination. But resistance towards this discrimination is essential for their recognition as “quirky citizens” (Bumiller 2008) and for showing how our anxiety on “capacity” interacts with a society increasingly guided by a neoliberal economy.

Following this argument, I will illustrate indeed how social contract theories draw on a threshold account of presumed universal capacities to define citizenship. Cognitive norms of autonomy, empowerment and practical reason have important implications for people with intellectual disabilities as they underpin the reasons why they are not enjoying full civil rights and are not acknowledged as citizens. Barnbaum (2008), for instance, wondered if a theory of mind is crucial in order to develop a sense of relatedness and social belonging and if morality always implies a sympathetic identification with other people’s feelings and needs. She showed indeed that also “normal people” show moral detachment and carelessness likewise people with autism, who might seem not concerned with others because of their difficulties in the understanding and application of moral and social rules. It is, instead, a narrow description of the human as a moral agent that restricts some individuals from being included in the designation itself of “worthy humans”, who thereby fail in meeting the criteria of personhood:

“Persons” are those individuals who should be given a certain moral standing, such as moral rights; the set of “persons” may not be co-extensive with the set of “humans” (...) [as if] some biological humans are not worthy of the same consideration as others humans” (idem:71)

Martha Nussbaum (2006) addresses the issue of human worth, agency and moral obligation in her well-known “human capabilities approach”, a theoretical tool that aims at improving social contract theories that come up short when considering “marginalized subjects” like women, disabled people, social justice or animal rights. She provides a set of enabling conditions that we must ensure in order to access citizenship (idem:76-77) such as lifespan (1) bodily health (2) and integrity (3), the freedom to use senses, imagination, and thought (4), the capacity to feel emotions, attachment and love for others who care for us (5), practical reason, that is the ability to form a conception of the good and to engage in critical reflection about the planning of one’s life (6), sense of affiliation (7), relatedness (8), humour and play (9) and control over one’s environment (10). Her argument about “what a full and meaningful life is” presupposes thus a view of individuals as beings enabled by their bodily and cognitive capabilities and

equipped with a functional “decision-making process”. This assumption has important implication for people with autism and intellectual disability. Indeed, a life without these capabilities is “not a life worthy of human dignity” (idem:78). For instance, with limited ability to imagine and recognize others’ beliefs and intentions as well as by showing difficulties in self-determination, moral commitment and practical reason, persons with autism do not seem to possess many of the capabilities necessary to a life that is worth living. At this regard, I think crucial to draw attention to Nussbaum’s definition of practical reason as the “key architectonic entitlement in the case of human beings [that] pervades and informs all the others, making their pursuit fully human” (idem:398). As underlined by Barnbaum (2008), Nussbaum appraises that the capacity to frame goals and projects and to plan life is necessary to be considered as fully humans and those individuals who altogether lack this ability “including what is good and how one should live [...] would not be likely regarded as fully humans, in any society” (idem:82).

Nussbaum’s intention was to provide a social contract theory able to address social justice for marginalized subjects as people with intellectual disability and “shifting disability from an attributed problem in the body to a problem of social justice was theoretically ground-breaking” (Garland-Thomson 2011:592). However, she failed to question “capabilities” as pre-requisites for humanness and equality. She does believe, instead, in a sort of compassionate responsibility of society. Despite bestowing citizenship on people with mental impairments, Nussbaum shifted the spotlight on the idea that it is a duty of any “decent society” to do owe certain obligations towards those who are not deemed “fully human” and “to address their needs for care, education, self-respect, activity, and friendship” (Nussbaum 2006:98). Like Nussbaum, also Wong (2009) shift the emphasis on the duties of justice that we as a society have towards people with cognitive disabilities. The conceptualization of citizenship and political participation of both these authors ground thereby on taken-for-granted assumptions about cognitive capacity.

When it comes to intellectual disability, the critique of Nussbaum’s capabilities approach mainly lies in the fact that social contract theories imagine individuals as contracting agents with a rather idealized rationality and as fully cooperating members of society (Kittay and Carlson 2010). Similarly, Rogers (2013) argued how Nussbaum still “draws from the social contract tradition, which is challenging, largely because it cannot accommodate intellectual disability, due to the fact that agents are said to be independent, free and equal and assume to enter this “contract” for mutual advantage” (idem:992). The citizenship theories based on

capacity contract equated indeed disability with incapacities and incompetence. In doing so, exclusion and discrimination on the basis of disability are still widely accepted forms of oppression as they were an inevitable consequence of people's failure to be full humans. Carey's (2009) book "On the Margins of Citizenship" is quite interesting in this regard as it argues that disability policies tend to sustain an "ambiguity" that simultaneously promises rights yet also allows their retraction. Indeed, by considering the history of the fights that parents, self-advocates, and professionals fought for civil rights for people with intellectual disabilities throughout the twentieth century and the changes that took place over that time, she eventually argued that though living conditions for persons with intellectual disability have changed dramatically, fundamental human rights are still violated in many aspects of their everyday life.

Anthropologist Stacy Simplican (2015) criticized feminist interventions - such as those of Nussbaum and Wong - on social contract theory for still excluding the most severely disabled from the exercise of rights and for having contributed to an ableist ideology that stigmatizes people with intellectual disability through implicit biases about intellectual capacity. In this regard, she argued how for having fabricated capacity-based citizenship concepts, liberal policies have prevented egalitarianism and the inclusion of people with intellectual disability in society. Indeed, scholars of the social contract taken as a given that capacity contract is still central to political membership, conceding to those deemed as falling below this capacity threshold only charity and compassion. As a consequence, our democratic political system ends up excluding anyone who falls below a supposed a cognitive threshold and conversely, people's supposed incapacity or intellectual vulnerability is crucial to justify social protection politics. Therefore, according to Simplican, the capacity contract has been used as a "domination contract" by using standards of capacity to exclude people who are not deemed worthy to exercise rights.

However, the issue of a liberal philosophical tradition of citizenship is not the capacity requirement in itself. For instance, some people with autism rather than rejecting altogether this prerequisite have instead laid claim to citizenship on the basis of their "different" capacities, appealing to Lawson's (2003) concept of *diffability*, a neologism that highlights a person's different or special abilities. Nevertheless, as I pointed out throughout the thesis, this is the case of people having so-called high-functioning autism (formerly Asperger syndrome), who advocate for their civil rights by working within the boundaries of the liberal tradition and fight,

more precisely, to re-define and expand the definition of capability in order to include people with a broader range of cognitive and sensitive abilities. Even this strategy rests thereby on the continued assumption that there exist some people who are “truly” incompetent, that is people with severe intellectual disabilities and somehow deserves to be excluded.

According to Simplican (2015), people with intellectual and developmental disabilities subvert idealized cognitive expectations - such as cognitive deliberation, logical reasoning, and analytic reflection - and reveal the fictive political subject from which they emerge. In doing so, disability produce *anxiety* with regard to capacity contract as it “reveals the deep discrepancy between the ways we conceptualize the demands of political participation and the actual range of ways people really act politically (...) [and] between the ways we as democratic citizens idealize cognitive capacity as trusted democratic resource and our realization of the vulnerabilities besetting our cognitive capabilities (idem:3).

This anxiety about disability can be used as a political resource insofar it pushes us to resist measuring people for their inner cognitive consciousness and to understand instead agency and empowerment through people’s actions. By questioning this naturalizing of capacity as inherent for political membership, she asks not simply to recognize how the capacity contract has been on the basis of different kinds of oppression, but instead to personally engage with daily forms of oppression of disabled people which could otherwise remain hidden or naturalized. Drawing on Hannah Arendt’s conception of political action as spontaneous, plural, and public (idem:110-115), Simplican’s ethnography explores political agency among self-advocates by considering the strategies they use to successfully enhance inclusion and participatory access. These strategies include thick alliance, humour, and dance (idem:122-132). While the thick alliance between people destabilize the assumptions about expertise and accord respect to the knowledge people with disabilities have regarding their lived experience, needs, and interests, dance and humour provide other means to disrupt hierarchy, destabilize ableism, challenge norms, express joy, and build embodied connections. Simplican emphasizes the value of participating - and simply being - in public as an act that resists society’s relentless attempts to erase disability and hide people with disabilities. Despite some self-advocates may not use the same linguistic and behavioural tools expected in mainstream politics and may also seem to fall short of the requirements of the capacity contract as they may misunderstand information, fail to abide by professional norms or rely too heavily on advisors, they are nevertheless presented as pressured to present themselves as competent. This is why self-advocacy movement itself

may potentially enforce the capacity threshold. Therefore, despite her criticism of feminist thinking on social contract theories, she ended up failing too in addressing intellectual disability and citizenship, as she did not take into account the cases of severely intellectually disabled people. Her credit lies, nevertheless, in having shown how the recognition of human vulnerabilities may prompt us to join in alliance and to co-work for social change and political action. With regard to this point, Simplican states: “[if] the domination capacity contract highlights all those who fail to comply with compulsory capacity, the solidarity capacity contract is (...) a practice, as we imperfectly aim to understand our interconnected political aims” (idem:122). A conception of citizenship shaped by notions of rationality and capacity leaves indeed key issues of power, access, and participation in rights unresolved.

Broadening citizenship spectrum

In what follows, I will evoke parents’ claim for the broadening of the meaning and value of citizenship. This claim, actually, has a double aim. On one hand, parents demand to broaden the sense of citizenship in order to give value and voice to human diversity, to welcome different form of sociality, and thereby to assure rights for people with autism and so-called cognitive impairments. On the other hand, they demand us to educate and train our willingness to be affected by others’ needs - such as disability rights advocacy - as an intellectual, moral, social and political collective achievement, challenging us, thereby, to rethink our role as citizens.

Parents care about showing how living with a person with autism educated them for understanding, tolerance, respect, acceptance and appreciation of diversity. They also learned about the urgency to change society’s mindset about disability in order to do not perpetuate a deficit-model thinking that conceives people with disabilities as mere unproductive or needy persons. After almost a year since we first met, Irene’s only expectation about the future of her son Osvaldo lies on society’s will to change and create other paths for encouraging people, beyond any kind of eccentricity or dissimilarity, to take enjoy their diversities and opportunities. Seated on a public bench for a good long conversation, during which I expressed my deep appreciation for her lifetime commitment, she regrets the enduring absence of recognition of the value of parents’ stories and perspectives. Pedro too was always particularly severe on this topic during our talks:

“people are complicit in this “ghetto-family” situation (...) state-run institutions where disabled people are warehoused are not only the proof that the state still justifies isolation but also of society’ inability to accept autistic people and to listen to us who are actually living with them, it’s a huge nonsense! society is still afraid of mental disease, of disability, whatever...we are even afraid of elderly people, would you even imagine?!” [mockingly shaking his head]

As well as other parents, they suggest addressing family’s role in supporting and fighting for rights to reveal how citizenship intersects in the real experiences of many people with disabilities. Family members often cloak care with an aura of beneficence and ignore their harm and sacrifice, while they may gain respect and public prominence from their own stories of living with children with autism. As I shown in Chapter III and IV, parents considered themselves the only entitled to claim for their children’s right to live in the community as well as to gain access to social funding and services, education and healthcare. Beyond addressing what rights people with intellectual disabilities should access and the means by which we - as a society - should determine this, parents claim to reflect not only around the social obligations we have towards those who cannot fight for or exercise particular rights but also to the opportunities that people with autism can give us. The absence of attention for the opportunities that society might gain by providing people with autism as well as intellectual disabilities the macro enabling conditions of citizenship leaves these latter and their allies alone. Contemporary social systems seem, indeed, more concerned with social protection and obligations, contributing in this way to reinforce the mainstream and disruptive idea that disabled people are worthy only of protection and benefits. In this regard, in his everyday relations with friends and parents of his son Luis’ classmates, Diogo hope to overcome the idea that financial support for people with intellectual disabilities is a threat to the economy.

Similarly, as Head of the Cabinet of the Secretary of State for the Inclusion of Persons with Disabilities, Ivo uses his institutional role for promoting the idea that health-care and social-support costs are a valuable investment for the preservation of society’s diversity itself and an instrument against eventual eugenics measures. Many parents, actually, admitted fearing that advances in autism genetics may lead to the identification of genetic markers and thus to the employment of prenatal genetic tests, eventually leading parents to choose abortion. This eventuality may threaten the presence of autism diversity and silently lead one day to a genetic homogenization of humanness. I also remember Emanuele’s eyes, widened and filled with deep visible concern with regard to an eventual use of psychotropic drugs able to influence brain

mechanism or “in some way substitute the neurological functions”. He supposed indeed that these advancements could violate the uniqueness of every human being:

“science goes incredibly fast and it should give means that better autistic people’s lives, but we should think about to what extent this would also have not so positive effects, I mean the path that my daughter Isabella has followed since she was born, that’s shouldn’t be substitutable, it’s part of her!”

When interrogated more directly around the issue of citizenship, parents of children diagnosed with autism associated with general intellectual disabilities drew on a common concern: they know their children will never fit or achieve citizenship as it is required by mainstream criteria such as capacity, competence and productivity. As brilliantly argued by Fontes (2014), insofar as a capitalist mode of production dominates our society, “the attribution of rights is not enough to eradicate the exclusionary nature of citizenship, since their enforcement is still compromised by the capitalist system” (idem:1407). For instance, Francisco - the son of Pedro - shows significant speech and cognitive delays. According to his father, he has “no idea what it is to be a citizen as he doesn’t intervene to the point of being a citizen with civil rights”. Then, it is crucial to assure him school and care access as a way to “enjoy his rights to be in society”. Despite welcoming state-run initiatives of sheltered or supported employment⁷⁰ for people with autism, he particularly disapproved the idea that work and productivity should represent the only means for social participation:

“this idea of getting them a job or enrolling them in a whatever workshop just to keep them busy...this does not mean that they finally grab life by the horns, maybe my son will never work in this life, this idea of what is a normal human being is so terribly present in the language we use...there is still a lot of work to do...we say, the functionality of people with autism, he is not functional, autistic people don’t produce, don’t contribute...there is so much to do in terms of education and citizenship, of which kinds of citizens we “normal” are first of all!”

Similarly, he questioned the idea of citizenship as a mere exercise of rights, such as voting. Indeed, instead of thinking if his son Francisco will be able to choose and vote, he wondered

⁷⁰ While supported employments represent a well-defined approach to helping people with disabilities participate in the competitive labour market, helping them find meaningful jobs and providing ongoing support from a team of professionals, sheltered employment lie in more segregated programs designed to help individuals who are not able to work in a competitive employment setting. Sheltered workshops, day treatment, and work activity centres are examples of sheltered employment programs. Font: www.nami.org

“would that be important to him? Does his well-being depend on it?”. Pedro argued indeed that sometimes parents’ frustrations about citizenship and future of their children depend on the idea of normalcy that we as a society have, and he firmly concluded, “We should not wait for our children to look like the idea that we have because maybe that’s not what’s important for them!”. On this subject, I will report some audio-notes I digitally recorded when drove away from Lucia’s parents’ house after her son Paulo’s birthday party, to which she kindly invited me. Paulo was playing with two older cousins whose grandparents particularly encouraged them to appease their younger cousin’s fetish with automobiles. After Lucia told her family about my general interest in citizenship and disability rights, her father, a retired teacher, agreed with the idea that when speaking about citizenship rights and intellectual disability - unlike physical disability - we call into question the ability to decide, to think, or to choose and thus implicitly the very idea itself of person. As I saw Lucia very emotional and in discomfort with her father’ words, I preferred to divert the attention on children’s very noisy games. The day after, she contacted me through Facebook chat in order to apologize for her very emotional reaction and to eventually express to me her “real” concern about what society thinks that a person with cognitive impairments can actually do:

“This is a very complex but also very dangerous issue, you know? because say that these people can exercise all the rights is simplistic, it’s an illusion...but this means for me that society should adapt herself to the needs and capabilities of people who are different, also normal people don’t have the conditions nor the civic education to vote, they are not prepared...that’s to say that we take for granted normal people’s rights and never ask ourselves if we are actually able to exercise these rights, if we have the awareness, sensitivity, and education to fulfil our rights, that’s the point! this idea that people with disabilities are not able to choose, I can tell you that this is bullshit! sorry, it’s not true, Paulo doesn’t communicate with words, but he communicates with his eyes, with his own body and I understand him because I do an effort for a mutual adaptation between me and him, and this has also to be seen as a strategy for society and people with disabilities, we need a mutual adjustment! there is no need to create a “world for them”...this...this reminds me again this idea of hygiene, you know? you have your clean and comfortable space and everything else is invisible! The point is that my fight should become a collective struggle, but Portugal is still very far from even thinking about this, we just talk about “awareness” or “inclusion” because it’s politically correct, that’s the truth!”

Furthermore, Lucia disagrees with the idea of “inclusion” because Paulo - as she said - is “already part of society, the world belongs also to him”. She usually prefers to talk about

“integration” as a way to underlying society’s duty to recognize the skills and the “pace” of people with autism and integrate them as part of its values. As Pedro and Irene, she also emphasises society’s potential benefits from creating a more affordable environment but also a new broader sense of citizenship that looks at disability as an improvement for humanity:

“who knows what these people could give to humanity if they had the conditions to show their value - she eventually wrote me - what deeply frustrates me but also motivates me to keep my battle it’s that [disability] is always seen as a problem, as something to “settle”, it’s a “bummer” and never as an opportunity for everyone to be a better citizen!”.

From what I reported so far, parents demand that society is willing to recognize disabled people’s rights so that these are no longer considered a private matter. Disability, as Pedro said, compels society to be more accessible, ending up to better and improve everyone’s life. To support his “philosophy”, namely that what is good for people with disabilities is better for the whole society, he compared the building of an “autism-friendly” neighbourhood or street (that is, a place built so to avoid sound and visual hypersensitivity) to the first bicycle streets appeared in Lisbon: “at the beginning we thought it was crazy, nobody rode a bike and we were angry to spend all that money during the crisis but look now how many cyclists!”. Similarly, Irene hopes that in the near future also society at large, and not just family members, will become more involved in social media activism and promote disability rights in order to strengthen parents’ struggles: “I also fight so that others had the obligation to look at and care of them [disabled people] so that the State will hear that we all want new measures to improve disabled people’ inclusion and quality of life”, she said.

Pedro and Irene are particularly critical when it comes to Portuguese society’s knowledge, education and willingness to accommodate the challenges living with people diagnosed with a disability, but also to recognize its strengths. Pedro, for instance, who particularly like dancing told me he never thought about disabled people’s same desire until his son Francisco was born: “Suddenly I started to worry about people on a wheelchair, about blind people...imagine deaf people in a disco? people may think it’s too freaky but no, it’s not weird! Because everyone likes dancing, isn’t it!” For him, people with autism as well as people diagnosed with other mental disorders are not yet part of our society because of people’s indifference but also lack of a “sentimental education” - namely, the emotional proximity to other desires or ways to express the self - which precludes people to be ready and able to “recognize others in their own

dignity”. The morbid curiosity that keeps people look at autistic children in public spaces, the dismay of their faces, the awkwardness and discomfort that the proximity with people with disabilities often arouses, the paternalism or the repulsion represent for him its symptoms. Consequently, he looks forward to a collaborative social engagement, underlining how parents’ advocacy - especially for single parents like him - can change things “only with the support, comprehension, and efforts of people at large”. Individuals’ different ways of living and expressing one’s personality should represent, thereby, a fascinating resource that motivates society to widen its horizons and to acknowledge people others’ lease of life: “that will be a civilisation’s mark, a proof of progress! This is the kind of hope that I like!”, he passionately concluded. Likewise, Irene calls for a more conscious participation of people instead of “a mere circumstantial worry” that emerges when crossing someone who has autism or during Christmas fairs when people buy solidarity project’s products just to do “the good action. She demands, in other words, society to move from few occasions of awareness to more conscious and engaged participation, so those younger generations will learn to acknowledge and support people’s different needs and features as a taken-for-granted value. This mindset’s change could finally lead people to look at differences not as a threat but instead as a strength on which society leans for constructing its future generations:

“the proximity with even radical differences is enriching for all of us as we learn how to cope with our fears and preconceptions...imagine a classroom with kids from various countries, with different disabilities, various religions...it’s a more stimulating environment than...I don’t know...than a school with all kids neat, blond and blue-eyed! And we all know where this latter situation goes, don’t we? [alluding to population’s hygienic measures]”.

Before concluding, I will report the considerations of two other mothers whose discourses referred to the idea of changing citizenship values at large. Along with a discussion thread within the *Os Amantes de Saturno*’s page about parents’ efforts in their everyday life to talk with strange people about their reactions of proximity with their children, Rute expressed quite frankly that society’s education is a priority in order to build a more engaged citizenship. She argued, in particular, how there will always be inequalities in disabled people’s opportunity to live a relatively good future unless we revert their dependence on family. Luisa intervened by writing how in daily life we are still uncomfortable and unable to cope with intellectual disability: “nobody educated us” - she wrote - “how to approach people with disabilities, unless you have one in your own family [...] we should say that we are good citizens only when we

really act to avoid someone's exclusion". As I took part in the discussion and as I have already created with both of these mothers a trusted virtual friendship, Luisa asked me to enter the chat box in order to add some of her further considerations on the subject:

"the richness of life lies in the celebration of differences and in the humility of recognizing how much we have to learn from each other...of course this is simpler with regard to people with Asperger...but we are looking to achieve a situation in which we don't separate the future of people with disabilities from the future of people without disabilities, these two groups don't make sense if disconnected, because we all have our needs, strengths and qualities"

Conclusions

The narrative accounts I gathered during my fieldwork on autism advocacy suggest me that parents generally claim for a further development of citizens' awareness in order to challenge notions of disability in order to welcome it not as a burden but rather as a difference that could improve human social and political development. Parents propose, henceforth, an alternative ethic of citizenship sensitive to other people's needs and claims and whose practices are focused on fairness and equality, attentiveness and care. A society committed to broadening its "spectrum of citizenship" supports all its members to flourish as unique individuals and to contribute to their community according to their possibilities and qualities. As such, having an intellectual disability does no longer represent a barrier to citizenship but instead, an opportunity for communities to come together, play out social change through practices of affection and alliance. Through social media activism, parents voice their claims and manage autism's visibility as a social and political issue by building and maintaining a "contested" or "dissident" posture over time (McCosker 2015). They want to contribute to the emergence of an "enlarged" notion of citizenship by relying on people's openness to being affected by others' fights, needs and claims, on people's availability to epistemologically and politically challenge their taken-for-granted assumptions about disabled people. By boosting the importance of being involved, parents hope to promote the coexistence of people with different virtues and vulnerabilities.

What kind of possible theoretical scenarios may be foresight from parents' call to enlarge our spectrum of citizenship? As an anthropologist and thanks to the parents I had the chance to encounter and to dialogue with during an almost two-year fieldwork, I will draft in what follows some reflections that could contribute to this open-ended and challenging issue.

I think there is a crucial and affirmative interplay between parents' activism and the legacy of critical post-humanist feminist approaches to disability. Both argued that the bodily encounters are the potential places where a new sociality - open to intellectual disability and to human diversity - can be produced. The acknowledgement of parents' narratives and advocacy practices has indeed both epistemological and ethical implications. Their discourses and actions should inform society's understanding of disability and offer an inclusive concept of humanity

that potentially could guide law and politics. We cannot ignore how disabled people still experience discrimination in many contexts and they are still regarded as objects of charity rather than as subjects with equal rights. Society at large needs to broaden its understanding of disability in light of a notion of human diversity that embraces disability as a human experience and condition. Moreover, Wilkinson and Kleinman's (2016) invitation to nurture our "passion for society" as anthropologists implies the possibility to elevate the claims and worries of the "subjects" of our ethnography to legal issues. Therefore, we can also use our deep understanding of diversity to denounce enduring forms of social stigma, disqualification and exclusion, as well as to politicize it and to reveal its structural and epistemological aspects, whether spread by state institutions, media, or in public space. Mistrusting, unrecognition and discrimination represent practices constraining agency, always. Autism spectrum disorders, as well as other developmental and intellectual disabilities, arouses political and moral issues that we should address in order to multiply the possibilities of society to be(coming) affected by them. Citizenship rights, thus, matters for people with disabilities, otherwise they inevitably fall into the category of socially worthless people. The discussion about the political and moral meanings of intellectual disability, its public disclosure, the support for educational programs, the need to spread disability awareness and to fight stereotypes represent practices that could reverse the loss of opportunities and improve people's rights access and quality of life. Finally, I think that anthropology, when connected with social justice and social inequalities' discourses, can contribute to build a greater cultural tolerance towards difference by criticizing the current neoliberal phase of capitalism, which portrays individuals' value and life' aspects in terms of mere productivity and competitiveness.

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