‘Bodies that never grow’: How psychiatric understanding of autism spectrum disorders affects autistic people’s bodily experience of gender, ageing, and sexual desire

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ABSTRACT

This paper investigates the intersections of gender, sexuality, ageing in the way autism spectrum disorder is medically described as a discrete category. On one hand, the construction of autism as a male-centric phenomenon results in a significant gender gap in autism diagnosis, with girls diagnosed with autism significantly less and later than boys. On the other hand, the focus on depicting autism as a pediatric condition exposes adult autistics to discriminatory practices such as infantilization and contributes to the disregard of their sexual desires or to the misconception of their sexual behaviors as dangerous or inappropriate. Both infantilization and the supposed inability of autistic people to “fit” into adulthood have a significant impact on both sexuality’s expressions and ageing experiences. My study suggests how fostering knowledge and further learning on the infantilization of autism can bring important insight into understanding disability from a critical angle. By challenging normative notions of gender, ageing, and sexuality, autistic people’s different bodily experiences question medical authority and social politics and criticize the public representation of autism in the broader social space.

Introduction

The medical category of ‘autism spectrum disorders’ (ASDs) refers to a wide range of conditions in terms of symptom type and severity, co-occurring medical conditions, and reflects the heterogeneous support, needs, and strengths that each autistic person may experience. Restricted interests, repetitive behaviors, difficulties with social interaction and verbal communication, and other behavioral, neurological, and cognitive atypicalities are just a few of the characteristics of autistic people. ASDs is typically diagnosed in early childhood and is a lifelong condition. The medical/pathology paradigm has so far dominated the discourse on autism. This paradigm frames autism and other neurocognitive functioning variations that significantly deviate from socially constructed standards of “normal” as medical pathologies, deficits, and damages, which explains why autistic people have long been portrayed as lacking, deficient, and abnormal (Bumiller, 2008). The neurodiversity paradigm, which views autism as one type of variation among many different types of minds, has been suggested as a potential substitute for the medicalized view of autism (Pellicano & den Houting, 2022 for a review).

Additionally, the very first biomedical descriptions of autism as a distinct psychiatric disorder portrayed it as a male and childhood condition. The media’s portrayal of autism and more recent biomedical theories on its aetiology have reinforced this trend by continuing to place a strong emphasis on male children. Scholars have provided a critical analysis of the detrimental effects of gender disparities on both autism’s understanding and representation (Shefy, 2015) as well as the connection between the underrepresentation of autistic adults in the media and practices of infantilization (Stevenson, Harp, & Gernsbacher, 2011). Regarding gender issues, more recent scholarship has reviewed recent findings regarding sexuality and gender in autism (Sala, Pecora, Hooley, et al., 2020) and highlights the significance of acknowledging differences in sexual desire and intimate relationships in autistic people who, when compared to their typically developing peers, may show some difficulties in developing skills necessary for these types of relationships (Pecora, Hooley, Sperry, Mesibov, & Stokes, 2020). Other

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1 In line with the social model of disability and in order to reflect the autism community’s preferences in terminology (Brown, 2011; Bury, Jellett, Spoor, & Hedley, 2020; Kenny, Hattersley, Molins, et al., 2016; Sinclair, 2013), throughout this article I use identity-first language (autistic) rather than person-first language (person with autism/disability).

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researchers focused specifically on the effects of gender on the diagnosis and treatment of autism in women and adolescent females (Green, Travers, Howe, et al., 2019), and how the latter are more likely to display camouflaging (i.e., exhibiting female-gender-typical behaviors), which has important implications for the understanding of the intersection of gender diversity and later diagnostic timing (McQuaid, Lee, & Wallace, 2022). As regards infantilization, studies addressing autism at the juncture of adulthood and ageing have increased noticeably, but they still represent a very small portion of the overall literature, which primarily focuses on autism in its childhood and adolescent stages of development (Wright, Brooks, D’Astous, & Grandin, 2013). Also, Akhtar, Dinishak, and Frymiare (2022) stressed how – even though the rise of autistic self-advocacy has helped to increase the representation of autistic adults in the media in the United States since the initial study by Stevenson et al. (2011) was published – the underrepresentation of autistic adults in the media is just one of many ways that infantilization manifests itself.

In line with this body of research, I will first briefly review the construction of autism as a medical disorder before focusing my analysis on two key issues: the role of gender bias and infantilization in the construction of autism as a discrete medical category and how these processes still influence the autism diagnostic process as well as the understanding of autistic people’s sexuality and ageing experiences. I then look at how alleged gendered behaviors and social expectations contribute to misunderstanding autism in women. Similarly, the misleading representation of autism as a pediatric condition together with a deficit-based conception of autistic people as lacking self-determination and autonomy risks silencing autistic people’s bodily experiences of sexual desires. Both autism infantilization and the supposed inability of autistic people to “fit” into adulthood affect how autistic people are perceived to age and experience sexuality, making them less likely to receive social support and services and more susceptible to social exclusion. My ethnography suggests that by showing non-conforming gendered behaviors as well as a non-normative path of navigating the transition to adulthood, autistic people challenge social expectations and the misleading portrayal of themselves as “bodies that never grow”.

By acknowledging disability as the result of unjust interactions between a person and her social and political environment, we can critically address society’s normative values and their correlation with social inequality and discrimination. Anthropology’s emphasis on social and political dimensions of disability (Ginsburg & Rapp, 2013) has indeed important implications in terms of disabled people’s empowerment and citizenship, as it focuses on practices of mobilization against social exclusion and disqualification.2

Methodology and data analysis

In this paper I draw from narratives and interviews that I collected from parents of autistic adolescents who are transitioning to adulthood. Before describing my methodology and data analysis, I think is important to provide some background on my fieldwork to clarify my position as a researcher. Research on autism has been criticized for its propensity to prioritize accounts from parents, teachers, or other informants and overlook autistic people’s narratives and understanding of their own condition and life experiences. I agree with the importance from an epistemological, political, and ethical standpoint of acknowledging autistic people’s first-hand accounts, however, there are several reasons why in this paper I did not include first-hand accounts. The data featured in this paper was collected during my PhD research project on the emergence of a parent-led autism advocacy movement in Portugal. My primary interlocutors were therefore parents. Moreover, all the children I met when speaking and/or interviewing their parents were minors and I was unable to interview them because of ethical concerns: I did not get the permission of either their guardians or my university’s ethical committee. Besides that, some of the children I met were non-verbal or had limited verbal skills and I had any specific abilities or specialized knowledge of non-verbal communication.

For that project, I carried out 14 months of fieldwork (between 2013 and 2015) and interviewed 19 parents (15 female and four male) of autistic children who became disability rights activists, many of which were active in online spaces as they belong to online advocacy communities hosted by social media platforms like Facebook. My research methodology then combined a nethnography (Kozinets, 2010) with an ethnography in non-virtual environment. I realized both face-to-face and online conversations, participated at autism events (like conferences and celebrations), advocacy-related activities (such as marches and parliamentary questions), open gatherings, as well as conducted in-depth and semi-structured offline and online interviews [via email and Facebook].3 My interlocutors were white Portuguese citizens in their late 30s to early 40s, coming from a very wide variety of backgrounds and occupations but mainly hailing from the working-class and tertiary milieu. I met some of them thanks to the “snowball method” using virtual networks such as Facebook (Balter & Brunet, 2012) or through parents suggesting other potential subjects from among their acquaintances (Parker, Scott, & Geddes, 2019), by word of mouth with friends and colleagues and by the intermediation of the main autism association of the country, the APPDA - Associação Portuguesa para as Perturbações do Desenvolvimento e Autismo [Portuguese Association for Developmental Disorders and Autism]. Other parents were part of online autism advocacy groups, including Os Amantes de Saturno4 [Saturn’s Lovers] that represents the main Facebook-based autism advocacy and support community existing in Portugal and eventually where I have primarily engaged during my nethnography (Kozinets, 2010).

In the following sections, I will use three case studies of interlocutors (a clinician and two parents) who specifically discussed gender, infantilization, and sexuality in their narratives and interviews. My qualitative analysis primarily draws on the exploration of the research topics mentioned above to understand my interlocutors’ accounts through the intensive study of each individual case. For this paper, I moved backwards and forwards between interview transcripts, memos, the research literature, and my personal field notes on each case study resulting in a more in-depth understanding of my interlocutors’ narratives. All my interlocutors gave explicit consent to participate after being made aware of the goals of my research project. Were informed of the aims of my research project and gave their explicit consent to take part. Their participation was voluntary. To protect their anonymity, all their names have been altered.

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2 I follow here a ‘social model’ of disability (Oliver, 2013), which views this latter as the product of social and material determinants that disable people and prevent them from fully participating in society. This perspective arose from disability scholars’ critique of the so-called ‘medical model’ which, on the contrary, ascribes disability to a person’s physical and cognitive impairments and, as a result, normalizes society’s discriminatory attitudes against disabled people and conceals its failure to provide adequate and appropriate services (Goodley, 2001). The term ‘disabled people’ is then preferred to ‘people with disabilities’ as it implies that disabilities - rather than being inherent deficiencies - are actually the result of societal barriers put in place within the able-bodied communities.

3 For that purpose, I made a Facebook profile under my real name, mentioning my academic position as an anthropologist conducting research on autism advocacy.

4 I explained my intentions as a researcher to the group’s members and administrator, who eventually told me that I could join the online community for the duration of my fieldwork.
Gender bias in the clinical settings

Dr. Lopes is a child psychiatrist and has served as the CPS - Child Psychiatric Service’s director in Lisbon since 2000. The CPS first opened its doors in 1983 and since then the service has been housed in a white, prefabricated building in a neighborhood on the town’s northern edge. After painstakingly negotiating on its busy schedule, he chose a convenient time to meet, but right upon my arrival at the CPS, his assistant, a man in his 30s, informed me that one of Dr. Lopes’ medical consultations was taking longer than anticipated and that I had to wait in the waiting room. Two women were standing there with their toddlers, one of whom was a five-year-old girl playing with a huge tipper toy truck and trying to fill its rear basket with different plastic fruits. Her mother suspected she may have autism since she was two-year-old, but it has taken a while to receive a formal diagnosis. She complained that other health professionals and educators failed to diagnose her daughter’s condition during early childhood when autism is mostly diagnosed and did not acknowledge her gut as she stated, “they insisted that my baby did not look or act autistic”.

I thought back to this dialogue as I began speaking with Dr. Lopes and used it as an opportunity to question him about the difficulties he faces in his clinical work, particularly when the patient is female. He acknowledges, for example, a greater difficulty in identifying and interpreting some of the behaviors of female patients as specifically autistic traits: “a non-verbal boy at the age of two immediately arouses some concern, but the same cannot be said for a girl; she will most likely be considered shy or introverted, rather than autistic”, he eventually remarked. Shyness is then naturalized as a feminine trait while in boys - he further admits - is more easily and frequently interpreted as social avoidance, thus affecting the decision-making in autism assignment. Compared to boys - he further claims - “girls assimilate faster, they kind of learn even at an early age some mimicking strategies that they eventually use to manage some autism traits…they do eye contact for example, and so something may go unnoticed”, a phenomenon scholars refer to as “camouflaging” (see Hull, Petrides, & Mandy, 2020 for a review). Dr. Lopes’ narrative about the alleged greater difficulty in “detecting” autistic girls is deeply rooted in a longstanding stereotyped narrative about supposed feminine behavioral traits or specific character patterns such as a more marked shyness or withdrawal compared to boys of the same age. In the same interview, however, he continues “most of our diagnostic instruments, such as the questionnaire or even the guidelines we have received during our education have been designed with a male presentation [of autism] in mind, so in a sense, we have more familiarity with autism in males…but this also means that the responsibility to be able to identify and interpret autistic traits in little girls falls upon me…well, to let you understand how serious this can be!”

Dr. Lopes then acknowledges that another reason females are under-diagnosed is due to gender biases in the design of some screening tools, which may influence how clinicians conceptualize autism differently in males and females (see Muggleton, MacMahon, & Johnston, 2019 for a review). What is written about autism is indeed generally based on the narratives, experiences, and behaviors of male autistic individuals. Allison Shefcky’s editorial for “Autism” journal, for instance, opens as follows:

“If you were to imagine what a typical person with an autism spectrum disorder looks like, what is the first picture that would enter your mind? Chances are that the first person you will think of is a young boy” (2015: 131).

The first two scientific descriptions of autism show how from its very first emergence in psychiatric literature it has been described as a child and male-typical disorder. The article ‘Autistic disturbances of affective contact’ by Austrian-born American psychiatrist Leo Kanner (1943) is unanimously recognized as the first systematic description of autism as a distinct disorder. One year after, German psychiatrist Hans Asperger described a very similar condition which he referred to as ‘autistic psychopathy’ (Asperger, 1991(1944)). Eight of the eleven cases described by Kanner and all four cases described by Asperger were young boys. Over time, psychiatric and biomedical literature have well-versed this male-based account for autism, implying that the consistency of the gender gap in epidemiological studies represented the evidence for some sex-specific biological risk factors, even if the underlying mechanism through which these latter interact is not yet identified. British researcher Simon Baron-Cohen (2002) proposed the most popular and controversial explanatory theory of autism’s sex-based discrepancy, the so-called ‘extreme male brain theory’. According to his studies on social intelligence and pattern recognition - the two cognitive abilities supposed to reveal sex differences in the non-autistic population - women appear to score better than men on empathizing whereas men tend to systemize, notice patterns, and follow rules. He then found that autistic people generally have trouble with the former - guessing others’ emotional states and grasping social cues - but do well with the latter, suggesting that no matter their assigned sex at birth, they tend to be at the systemizing end of the continuum, that is an ‘extreme male brain’ model (Baron-Cohen, Richler, Bisarya, Gurunathan, & Wheelwright, 2003; Baron-Cohen & Wheelwright, 2004).

The cognitive paradigm in autism epidemiological studies still echoes today. Some scholars, for instance, have proposed the existence of specific biological mechanisms, such as a “female protective effect” which allegedly reduces autism incidence in female individuals, raising “the possibility of artificially inducing this protection as a therapeutic or preventive measure for autism” (Gockley, Willsley, Dong, et al., 2015: 1). Others have suggested that autism male prevalence may result from sex-based differences in four key cognitive domains (mentalizing and emotion perception, executive function, perceptual attention to detail, and motor function) yet explicitly implying the existence of gender bias resulting in women being under-researched (Lai, Lombardo, Ruigrok, et al., 2012). These epistemological attempts to construct theories about the predominantly masculine nature of autism have over the years garnered some criticism; not just for the assumption that men and women differ fundamentally and that these differences are measurable in laboratory settings, but also because they rely on psychological tests and questionnaires grounded in gender-stereotyped topics and tasks.

Only recently, the most recent and comprehensive meta-analysis of autism prevalence studies (Loones, Hull, & Mandy, 2017) stated that the higher ratio of males (3 males for 1 female) is most likely due to diagnostic gender bias, which means that women are at a disproportionate risk of being misdiagnosed, later diagnosed, or missed entirely as women and therefore denied access to the diagnostic support they may need.

Researchers suggested that “more sensitive measures to detect females’ characteristics” could benefit clinicians in the diagnostic process (de Giambattista et al., 2021: 10) and have a positive impact on women’s mental health and health services access. The key issue here, however, is that these studies rely on the assumption that male autistic individuals are more likely to ‘act out’ autistic-like behaviors like reduced prosocial behaviors or repetitive and restricted interests than female autistic individuals, who instead exhibit greater internalizing behaviors such as...
shyness and passive misbehaving.

Anthropological research has shown that the way we think and behave as female-born and male-born individuals is not biologically based, but rather the result of how society expects us to think and behave. Gender studies in anthropology have resulted in a large body of research focusing, among other topics, on the impact of gendered social expectations and gendered bias in women’s life experiences (see Mascia-Lees & Black, 2017 for a reference). The collection of behavioral patterns associated with gender roles then reveals the set of expectations (about social skills, abilities, tasks, attitudes, behaviors, and ways of acting) thought to be socially and culturally appropriate to an individual based on her supposed gender identity. It is important to note that also autism scholarship is increasingly recognizing that the naturalization of alleged gendered behavioral patterns is (re)produced in social contexts such as the diagnostic setting, influencing both the assessment process and the diagnostic outcomes (Burrows et al., 2022; Tsirgiotis, Young, & Weber, 2022).

In this light, the gender bias inherent in both the diagnostic process and in laboratory-based epidemiological studies can be then understood as the logical precipitate of how autism has been constructed as a social and cultural artefact. This androcentric lens still affects the conceptualizations, construction and use of the psychometric instruments Dr. Lopes described as being tailored on behaviors and traits stereotyped on a male-gendered type, so that the autistic symptoms of a young girl are not recognized as such, but rather as traits of an alleged feminine nature (shyness and introversion). By shaping the clinical setting, gender bias engenders systemic inequality for women in many aspects of daily life, such as unequal access to diagnosis and interventions. Their numbers remain significantly underrepresented not only because of the social construction and discursive reproduction of autism as a “male-centric phenomenon” (Shefcy, 2015: 132), but also, as my case study illustrates, because gendered behavioral expectations are constantly (re)produced by health professionals themselves.

**Transition into adulthood**

Zelia, a part-time librarian and a single mother of Leandro a 13-year-old boy, is a very proactive user of *Os Amantes de Saturno* [Saturn’s Lovers], the main Facebook-based autism advocacy community I attended during my ethnography. The day we met, Zelia was persistently recalling a report aired the day before on a national television channel entitled “30 disabled children see the sea for the first time”. The news report did not actually show children but rather adults with different disabilities, including some autistic people, enjoying a day at the beach with a famous Portuguese champion of kitesurfing. Since the night before, Zelia was feeling so much upset that she noticed, she did not address a word to Leandro from home till she dropped him off at school. We finally headed to a nearby cafeteria and as soon as we sat down, she re-posted the news on the *Os Amantes de Saturno* page to collect the community’s views about how the media representation of disabled adult people negatively affected them. Throughout the interview, Zelia occasionally snooped through her phone, feeling increasingly disappointed as she read the comments: “WHAT?! CHILDREN?!! Why is this still happening in the 21st century? This makes my stomach turn. We [parents] should be the first to revolt against this view on disability and disabled adults, why should we expect society to change or think differently? [...] Going to the beach or at the supermarket should be normal for anyone, so why is it still ‘news’ for adult autistics or disabled people? Society pushes autistic people to its margins and their allies to give up, but what hurts me most is that we feel good about adult autistics being treated like children because in this way we think to protect them [...] I want a different future for Leandro, and we should start by thinking about the language we choose to refer to them as this shapes the attitudes, you know, the actions we do towards our children... because they will definitely grow up, so they will not be children forever”.

She was sharing her emotional state so vividly that I felt compelled to express my own concern about the issue she was bringing up, namely the need to condemn condescending and offensive language when referring to disabled people as one way to dignify them and change societal perceptions of their inclusivity. Paternalistic attitudes towards adult autistic and disabled people are alarmingly spread in media and popular culture. It is then crucial the role of activist parents like Zelia who advocate in favour of a language able to respect adult disabled people and foster their inclusion to deconstruct commonplace moral bias against them. While being aware of his son’s difficulties in transitioning to adulthood, Zelia critically addresses society’s biased way of seeing autistic people as individuals lacking self-sufficiency, self-determination, and autonomy.

A deficit-based approach to understanding autism - together with the underestimation of the challenges autistic people face in their transition to adulthood - results in less access to social services and health assistance (Nicolaidis, Raymaker, McDonald, et al., 2013), lower employment rates (Hedley, Ujarević, & Hedley, 2017), lack of social networks and loneliness (Umagami, Remington, Lloyd-Evans, Davies, & Crane, 2022). Adult autistic people struggle living independently, finding a job, or managing social interactions in the workplace when these social expectations are calibrated to neurotypical population (Marriage, Wolpert, & Maringe, 2009). Along with a restricted neurotypical social milieu, adolescence involves different physiological changes and relational adjustments that are already hard to manage. The liminality of this transitional period is worsened by the scarce or precarious availability of social support services (such as sheltered workplaces or community living) and supportive relational networks. In other words, when it comes to future life scenarios, there seem to be few options available for individuals on the spectrum. This future uncertainty is particularly alarming for parents such as Zelia or Pedro, an English teacher and single parent, as in less than six years his son Tiago will be out of school, and services and supports adapted to his son’s age seem already hard to find. In Portugal, the public sector has very little budget allocation for supporting young autistic people and their families in making the transition from school or higher education to adult life. Over the last ten years, the Autism Portuguese Federation (FPDA-Federação Portuguesa do Autismo) has been promoted interrogation and public initiatives about life planning and employment strategies for autistic adults, but the results have been disappointing. During her mandate as president of the FPDA, Isabel Cottinelli Telmo has attempted to put strategies and plans in place to help autistic teenagers transition from childhood to adulthood; these efforts have been hindered not only by a lack of funding but also by the structural absence of the Portuguese government in promoting autistic and disabled people’s inclusion and providing alternative supportive measures and adequate social benefits. On that account, Pedro comments: “it’s for a reason that I metaphorically compare Tiago’s journey to adulthood to a ‘desert without a compass’. He is aware in other words, that most autistic adults still have lifelong difficulties locating services that are tailored to their needs, pursuing a respectable and independent life, and accessing long-term care. This void of support threatens the future, and it unfolds manifold dimensions of inequality. Pedro outlines a link here with the continued underfunding of local institutions which, in turn, do not fund reasonable adjustments for disabled people or, worse, push them towards vulnerability and an uncertain future. As autism advocates, parents try to challenge the structural oppression of disabled people and call for a more accessible society where they can flourish in accordance with their potential. Concerning the rise in the neurodiversity advocacy and disability acceptance movements (Peipus-Kapit, 2020; Sinclair, 1993), the autistic adult community has denounced how they still significantly receive less attention from both scientific and media coverage compared to autistic children. Autism’s face is, in fact, quite always that of a child. Academic papers and media narratives still primarily focus on autistic children and when rarely describe the experiences of autistic adults they often use a child-referred language. In this respect, Stevenson et al. (2011) showed the role played by the news and media industry, parents and autism
Infantilization can take on different forms: from changing speech patterns, such as using baby-talk or dumbing down vocabulary or not speaking directly to them but instead directing comments and questions to a parent or caregiver. Zelia and Pedro have both witnessed friends and relatives infantilizing their teenage autistic sons, by referring to them with terms generally used for children such as ‘little’, ‘baby’, ‘kiddo’ or with expressions revealing a judgmental opinion about their supposed age-related skills or cognitive abilities, such as “his mind looks like a five-year-old boy.” Whether intentional or not, infantilization has a huge role in shaping public ideas about autism. On one hand, it results in paternalistic attitudes or protective behaviors, putting the autistic individuals into a child-like role and perpetuating the stereotypes of them being incapable to take care of themselves. On the other hand, it also entails a dangerous consequence, namely, it demeans a person by silencing her wants and needs. As for autism, this has also to do with the very construction of the concept as a discrete psychiatric condition. As I have previously described, autism is diagnosed in early childhood and has been conceived - and then imagined - as a child condition. Psychiatric knowledge has often contributed to arise the infantilization of teens and adult autistic people by specifically and predominantly describing them not only as lacking but also as unable to fully develop self-sufficiency and autonomy.

Politics of disregard: the impact of infantilization on autistic people’s sexuality

Modern conceptualization of autism as both a social disorder and a disturbance of social relationships resulted from a specific re-articulation of the notion of the “social” occurred within 1980s psychology which 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 supposed to reveal socially abnormal behaviors, thus discovering a “hidden mass of socially pathological persons (...) whose differences were previously seen as non-pathological, unimportant, and/or simply went unnoticed” (idem:110).

Narratives applying a biomedical model see autism through a deficit lens, associating autism with a malfunction, lack of social competencies, childishness and lack of empathy, this latter being not just the ability to intuit other peoples’ feelings or intentions but also to feel connection and interest in relationships. According to Emacs, Darry, Walter, and Knupp (2010), this medicalized account of autism constructs autistic people as asexual or depict them as childishly when it comes to their own desires. In addition to the characterization of autistic people as ‘weird’ or ‘misfit’ people - which is already a stereotypical and narrow image that silences the complexity of autism as a spectrum of conditions and experiences - infantilization then also reinforces the idea of autistic people as socially unfit to sex and romance (for a recent review, see Correa, Castro, & Barrada, 2021). By portraying autism as a neurological impairment that involves a lack of connection and immature behaviors, psychiatric knowledge presumes autistic people’s inability to access romance and sexuality and contributes in such a way to depriving them of the recognition of their sexual needs and desires as well as to reinforce (sexual) ableism.

In my analysis of offline and online parent-support groups, young autistics and their families have difficulty finding a space to dispel their doubts about sexual and romantic experiences or to question ideas of sexual behavior that layer a normative view of sexual desire. Pedro’s son, Tiago, has once been called into the principal’s office as he allegedly tried to touch one of his girl colleague’s private parts at school. After receiving several complaints from other parents, Pedro was asked to ‘correctly educate’ his son Tiago to make sure that he did understand the meaning of improperly touching other people: “sex, masturbation, the sexual desire of autistic people” Pedro explains “are not openly discussed, just repressed because all this cause discomfort. I know Tiago acted improperly as the other kids did too because what happened has to do with the sexual harassment of girls at school, a general and very problematic issue that should be addressed generally. It is not specific to Tiago, you know... he did it because he saw other colleagues do the same [...] I’m a teacher and I know that girls are subjected to this kind of violence which unfortunately is normalized in some settings such as school...but it also occurs that Tiago is autistic and so this behavior which, you know, I totally condemn has generated much more discomfort.” As Pedro argued, Tiago deserves to have meaningful sex development and society should acknowledge his challenges while at the same time supporting him in fully living his sexual needs.

Educational materials for parents of autistic teenagers rarely include any information about sex and many parents advocate for the importance to fill this knowledge gap and encouraging their sexual development. Even when autistic sexuality is expressed it is portrayed as inappropriate or dangerous to non-autistic people and then should be discouraged or “managed” (Groner, 2012: 263). Questioning normative thinking about sexuality, which dictates how disabled bodies should express their sexual desire, can generate a better understanding of disabled people’s needs and desires. Indeed, sexual desire is still trivialized when associated with non-normative bodies. In this sense, while autistic people certainly show some difficulty to learn body boundaries and respecting consensual physical proximity, this has translated into a distorted description of their bodies as still childish, unable to self-control or regulate sexual desires (Gilmore & Chambers, 2010). So, when these latter are eventually manifested, they may look odd or rude or thought to arouse dangerous and uncontrollable behaviors. As Pedro describes, mainstream rhetoric sees autistic sexuality as disruptive; Tiago for instance is portrayed as causing problems for fellow students and his sexuality is described as inherently predatory, something that reaffirms negative stereotypes about autistic sexuality as dangerous and uncontrolled. This view together with the stereotyped misconception that autistic teenagers need to be “correctly educated” to experience and express their sexual needs contributes to politics of disregard for their sexuality. According to Pedro, this misconception led some parents to be overprotective towards their neurotypical children out of fear of what Tiago could do to them; nevertheless, he also attributes some responsibility to child psychiatrists and therapists in spreading among parents the idea that their autistic children should not be given much information about sexuality or relationship advice because “they are thought to be not naturally predisposed or interested in a relationship at all. Most of the time doctors, psychologists, therapists do not mean to be paternalistic, like intentionally...they may simply do things that way with the best intentions. But they also have a role in teaching our children about sexual consent, about saying ‘no’, about when someone is doing something inappropriate.” This stereotyped myth about autistic people being unable to ‘control’ their sexual desires, to feel connection and intimacy justifies disenfranchisement and denial of agency in their sexual life, depriving them of a fundamental part of their well-being. Infantilization

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6 The investigation found that 95% of photographs used by parent-run websites were of children, that characters depicted as autistic are children in 90% of fictional books and in 68% of narrative films and television programs and that the news industry featured autistic children four times as often as they should. Thereby, this medicalized account of autism constructs autistic people as asexual or depict them as childishly when it comes to their own desires. In addition to the characterization of autistic people as ‘weird’ or ‘misfit’ people - which is already a stereotypical and narrow image that silences the complexity of autism as a spectrum of conditions and experiences - infantilization then also reinforces the idea of autistic people as socially unfit to sex and romance (for a recent review, see Correa, Castro, & Barrada, 2021). By portraying autism as a neurological impairment that involves a lack of connection and immature behaviors, psychiatric knowledge presumes autistic people’s inability to access romance and sexuality and contributes in such a way to depriving them of the recognition of their sexual needs and desires as well as to reinforce (sexual) ableism.

7 According to developmental psychology, there are different types of skills (intellectual, emotional, social) that abled people learn according to different age rates. The concept of intelligence quotient or IQ, for example, is a score derived from a set of standardized tests developed to measure a person’s cognitive abilities by comparing with those of other people of the same age, allowing 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.
and stigma against autistic sexuality have therefore serious and further-reaching consequences when it comes to sexual needs. Pedro admits to having been a controlling parent, having trouble in leaving Tiago able to learn how to take care of and attain his needs: “It is hard to acknowledge” he says “but we dismiss our children’s desires and sexual experiences because of our need as parents of maintaining a certain control, you know, over our children because nobody wants to see his child get hurt, and we fear our children can be hurt by society.” Infantilization thus impacts autistic people’s sexuality insofar as it relies on the presumption that these are unable to “fit” into adulthood, make their own decisions or think for themselves: like children, autistic adults are thought to be cared for, monitored, and protected by others.

Conclusions

As a psychiatric label, autism has a contingent historical nature: it has been subject to, and thus reflects, the epistemological changes of psychiatry as a discipline that identifies, describes, and classifies certain behaviors as pathological. In this sense, Moncrieff (2010) has described the psychiatric diagnosis as a “political device” that, by designating allegedly socially deviant behaviors as “medical facts” (idem:371), serves as a social control mechanism. In line with the work of critical autism scholarship, I outlined in this paper how autism has historically been constructed as a ‘male condition’ and that gender bias in diagnostic criteria are still shaping psychiatric setting, resulting in a significant gender gap in autism diagnosis (Burrows, C., et al. (2022). A data-driven approach in an unbiased sample reveals equivalent sex ratio of autism spectrum disorder-associated impairment in early childhood. Biological Psychiatry, 92(8), 654–662. https://doi.org/10.1016/j.biopsych.2022.05.027

Parents’ accounts about how their children are navigating their transition to adulthood and sexuality have been analyzed to explore practices of marginalization (often silent and not visible), social isolation, moral judgments about disability, and the ways through which society refuses to question its own discriminatory practices. Despite the limitations of my analysis, which I described in the introduction, in this paper I illustrate how advocate parents have an important role in autism understanding (Holmín, 2014) and in changing the (temporary) established knowledge about it. They advocate for the replacement of a disabling and ableist language that describes their children as sexualized individuals. Support and advocacy groups gather epistemic communities that (re)produce and question medical authority and social politics, as well as negotiate and criticize how autism is portrayed in the public sphere. In this sense, their narratives contribute to dismantling a mainstream view of autistic people as trapped in childhood. By promoting understanding of and further education on their children’s difficulties, they offer an important insight for the development of a more diverse and accessible future for autistic people. As socially non-compliant bodies and subjectivities, autistic people indeed can bring new perspectives to critically think about how infantilization and ableism impact disabled people’s sexuality and ageing.

Data availability

The data that has been used is confidential.

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References


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M.C. Lo Bosco


