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Negotiating Care: Living Arrangements and Adults with Cognitive Disabilities in South Brazil,

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Article abstract

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Negotiating Care: Living Arrangements and Adults with Cognitive Disabilities in South Brazil^{1,2}

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Abstract

Assisted Living for adults with disabilities is a recent subject in both Brazilian legislation and public debates. Although still stigmatized by the idea that those who seek different living arrangements for their children would be abandoning them, the concern with both the autonomy of people with disabilities and the well-being of the caregivers has prompted this theme to gain force in public and private spheres. Drawing from an ethnographic work with mothers of adults with cognitive disabilities from Porto Alegre, Brazil, who constituted a group to demand governmental action regarding assisted living facilities, I propose a reflection on how such plea enables a further discussion on the way disability and care are enacted. I argue that by thinking of their trajectories through the care practices they entail, one can track the moralities surrounding their experience of motherhood and how they are telling of the way disability is dealt with in this specific time and place. Situating their claim within broader debates on institutionalization, I stress how their plea cannot be understood without a critical stand on ableism and the invisibility and devaluation of care work.

Keywords: Assisted Living, Cognitive Disability, Care, Brazil, Institutionalization

Résumé

Les résidences avec services pour adultes ayant des incapacités est un sujet récent tant dans la législation brésilienne que dans les débats publics. Bien que toujours stigmatisé par l'idée que ceux qui recherchent des modes de vie différents pour leurs enfants les abandonneraient, le souci de l'autonomie des personnes ayant des incapacités et du bien-être des soignants a poussé ce thème à prendre de l'ampleur au public et au privé. S'appuyant sur un travail ethnographique avec des mères d'adultes ayant des incapacités cognitives de Porto Alegre, au Brésil, qui ont constitué un groupe pour exiger une action gouvernementale concernant les résidences avec services, je propose une réflexion sur la manière dont un tel plaidoyer permet une discussion plus approfondie sur le handicap et la manière dont les soins sont donnés. Je soutiens qu'en pensant à leurs trajectoires à travers les pratiques de soins qu'elles impliquent, on peut suivre les moralités entourant leur expérience de la maternité et comment elles racontent la façon dont le handicap est traité à cette époque et dans ce lieu précis. Situant leur revendication dans des débats plus larges sur l'institutionnalisation, j'insiste sur la façon dont leur plaidoyer ne peut être compris sans une position critique sur le capacitisme, l'invisibilité et la dévaluation du travail de soins.

Mots-clés: résidence avec services, handicap cognitif, soin, Brésil, institutionnalisation

¹ This study was funded by the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior – Brasil (CAPES) - Finance Code 001. The present paper draws from preliminary findings of my doctoral research on intellectual disabilities, care, kinship, and time. As of this time, I am a Ph.D. Candidate in the Social Anthropology Program at Universidade Federal do Rio Grande do Sul, under the supervision of Professor Dr. Claudia Fonseca, to whom I thank for all the support.

² Previous versions of the present paper were presented at the IV ENADIR, in the city of Sao Paulo, and at the Illeme Colloque Franco-Latino-American de Recherche Sur le Handicap, in the city of Porto Alegre, Brazil.

Introduction

According to the 2010 census, 1.4 % of the Brazilian population is a "person with mental or intellectual disability," a group that represents approximately 2,670,581 people (SNDP, 2010). Despite the considerable number and the fact that the UN Convention on the Rights of Persons with Disabilities, from 2006, was passed as a constitutional law in Brazil in 2008, there is still a shortage of policies and political interest to follow through on concrete measures of implementation. Hence, the responsibility for those who are somehow more dependent due to a disability still falls to the families, with little or no support from the government (Fonseca & Fietz, 2018).

I have been conducting research focused on mothers who provide care for their children with cognitive disabilities into their adulthood since 2014³. Focusing on family relations, I engage on what anthropologists Rayna Rapp and Faye Ginsburg (2001, p. 535) call "the intimate arena of kinship" as an important locus of analyses for being "a site where contemporary social dramas around changing understandings and practices of reproduction and disability are of-

ten played out." Throughout the years, I have noticed a common concern among my interlocutors: where can an adult with disability live when not with family members? A preoccupation aggravated by the lack of public and private services regarding assisted or independent living facilities for people with disabilities in Brazil.

In this paper, I center my analyses on ethnographic work conducted in the city of Porto Alegre, Brazil, from 2015 to 2018 with a group of mothers who gathered to demand governmental actions regarding assisted living facilities for their adult children with cognitive disabilities. I will first situate their demands within broader discussions on the Brazilian Psychiatric Reform in an attempt to stress why the claim for assisted living can still be perceived as a form of familial abandonment by many. I dwell on how current Brazilian policies that centralize care practices in the family can stigmatize the plea for assisted living facilities.

I will then present the group mentioned above. Mainly, I stress how their plea cannot be understood without a critical stand on ableism and the invisibility and devaluation of care work. I argue that by thinking of the trajectories of the mothers and their children through the care practices they entail, one can track the moralities surrounding their experience of motherhood and perceive how they are telling of the way disability is enacted in a specific time and place. With that, I aim to draw attention to the complexities of relations marked by mutual dependencies and specific needs (Kit-tay, 1999) as both mothers and children age.

It is important to stress that by introducing the experience of mothers who feel overwhelmed by the work of care, I do not intend to present an analysis in which disability is perceived as a burden. I argue that such feeling arises not only from the specificities of being responsible for someone whose dependence is enhanced by particularities of the body-mind but mainly by a context in which such particularities tend to be rendered invisible. As stated by Alison Kafer (2013), in a world where able-bodiedness and able-mindedness are compulsory, disabil-

³ In the years 2014 and 2015, I conducted research with three women from a poor neighborhood in the city of Porto Alegre, Brazil. Focusing on their everyday practices and life trajectories, I centered my analysis on understanding the relationships forged by that experience, the impact of resource management and acquirement, and the gap between expectations concerning constitutionally-guaranteed rights and their enactment in daily life. This project resulted in my master thesis, "Deficiência e Práticas de Cuidado: Uma etnografia sobre 'problemas de cabeça' em um bairro popular" (Fietz, 2016). For my Ph.D. research I decided to broaden the scope of analyses to mothers of different socio-economical background. Thus, I have conducted fieldwork with the group mentioned in the present paper, taking part in their meetings, gatherings, and virtual forums. Since 2017, I also conduct fieldwork at a non-profit organization that provides leisure activities for adults with disabilities. I go there twice a week and take part in meetings, events, and activities promoted to the families. I have also accompanied two groups that have organized in the city of Porto Alegre to build their own living facilities, observed the monthly meetings of the Department of Persons with Disability of Porto Alegre's Health Secretary, and conducted interviews with members of the judiciary.



ity is represented as a tragedy that must be prevented. The author presents the idea of "imagined futures" as a way to better understand the specificities of that experience. In a world where disability is understood as something that must be avoided, that is not desired, it "too often serves as the agreed-upon limit of our projected futures." (Kafer, 2013, p. 27). With that in mind, I propose that my interlocutors' concern about the future is telling of the ways disability and care are enacted in Brazil.

Thus, following Disability Studies scholars, disability is here understood as the obstruction of full participation and interaction imposed by society to those who have physical, sensorial, or cognitive impairments (Diniz, 2012; Nuernberg & Mello, 2012; Ginsburg & Rapp, 2013). A political and relational category "created as a distinction from cultural ideas of normality, shaped by social conditions that exclude full participation in society of those considered atypical" (Ginsburg & Rapp, 2013, p. 54).

I also draw from scholars working with an ethics of care perspective who argue for the recognition of care and dependence as central aspects of all human relations since not all bodies can or will reach the ideal of independence as presented by liberal thought. Within this perspective, care, as a practice and a moral value, is no longer relegated to the private realm and becomes a matter of social justice (Kittay, 1999; 2011).

By focusing on the mothers, I propose an approach that takes into consideration the rights and experiences of people with disabilities and the rights and experiences of the mothers-caregivers as symmetric. As stated by philosopher Martha Nussbaum (2001), if adequate support for people with disabilities to live a fulfilling life and have access to all aspects of social life is urgent, so is the attention to those responsible for providing such support. The claim for assisted living is, I argue, an important site of analyses for holding both these dimensions.

The anti-asylum movement and living-arrangements: Deinstitutionalization and Assisted Living.

Since 2014 I have worked with families of adults with cognitive disabilities from different economic and social backgrounds. Despite the many differences, they share a common concern: as both parents and children age, they have to face a near-total lack of public policies for adults who need support to live what is commonly understood as an "independent life." Hence, parents of people with disabilities worry about helping their offspring to live as independently as possible and also about guaranteeing their children will receive adequate care when they are no longer available to do so. In this scenario, where or with whom their adult children live becomes a key concern.

The significance of this matter was first brought to me when I met a group of mothers that advocated for assisted living facilities. As stated in their promotional brochure, they got together in 2011 to "study the legislation regarding living facilities, support family members in vulnerable situations, fight for new paths for their kids and, especially, for places that shelter and care for them so that family members can feel in peace about the future." In 2013, they were formally organized as a group in the hopes of reuniting different organizations and people in the quest for dignified living conditions for "people with mental disabilities."

As advocates, the group takes part in many spaces where the causes of disability and mental health are discussed. This approximation between disability and mental health occurs for a few reasons. First, because the line between these two areas is often blurred, whether in people's experiences or in policymaking (Surjus; Campos, 2014), also, in order to create a network of people interested in their cause, the group never imposed any restrictions to whom could take part in their advocacy. Therefore, family members of people with various medical diagnoses, such as autism, down syndrome, mental retardation, schizophrenia, and bipolar disorder are part of the group.

It is important to emphasize that in Brazil, discussions on assisted living are connected to broader debates over the Brazilian Psychiatric Reform of 2001 (Federal Law 10.261/2001) and deinstitutionalization. Part of my interlocutors' goal is to challenge the frequent association between living away from family members and "being institutionalized." However, they understand that the lack of appropriate spaces makes it so that facilities that offer this kind of service end up being very similar to total institutions. Thus, the group often engages in heated arguments with healthcare and social assistant specialists who share a commonsense idea that a parent who does not want to live with their disabled child is a "bad parent."

The federal legislation mentioned above resulted from years of debates regarding mental health and institutionalization. Its promulgation was crucial for the development of health policies that promoted the reintegration of people who had been institutionalized into society. Above all, it had a central role in closing "insane asylums" and considerably reducing the number of hospitalizations by prioritizing continuous health care services to be offered close to one's home. Following a tendency that had been taking place in Western societies since the 1960s, there was a shift from an institutionalization paradigm to a service paradigm (Aranha, 2001) anchored in the ideas of rehabilitation and socialization.

One of the outcomes of what is also known as the anti-asylum movement and the consolidation of the Unified Health System/SUS⁴ in Brazil was the entrenchment of the Psychosocial Care Network (*Rede de Atenção Psicossocial-RAPS*), instituted by the Decree 3088 from 2011. It acknowledged the inexistence of adequate self-sufficient healthcare facilities and programs, initiating a health network of territorialized, interdisciplinary, and community services (Quinderé, Jorge & Franco, 2014). The network is composed of Centers of Psychoso-

cial Care (CAPS), Shelter Units (UA), and a limited number of beds in regular hospitals reserved for mental health patients.

Therapeutic Residential Services (SRT) are also part of the network. Established in the year 2000 by Decree 11, they are meant to become a "home" for those who have been in mental institutions for two years or more. In a clear opposition to the "total institution" model, the law determines that each house must have a maximum of eight residents, be near to a Center of Psychosocial Care, and located in an urban area so that residents can progressively reconnect to the community they are part of (Silveira, Santos Júnior & Macedo, 2011).

However, not only people with mental health issues were institutionalized. For centuries, these often overcrowded, isolated, and inhumane total institutions were the favored solution to deal with those whose bodies escaped the so-called "normality" (de Paula, 2008). Therefore many people with disabilities lived most of their lives in institutions and, after years of confinement, no longer had family ties. Once the deinstitutionalization process started, they had no place to go back to. Just like the Therapeutic Residential Services (SRT) were envisioned to accommodate people with mental health issues with no family ties and in a vulnerable situation, assisted living facilities were conceived for people with disabilities in similar situations.

The Inclusive Residence Service (*Residência Inclusiva-RI*) is regulated by the Resolution 109 of the Social Assistance National Board and its consolidation was one of the goals of the National Plan for the Rights of People with Disabilities that started in 2011. They were envisioned to accommodate people with disabilities that are in a situation of "dependence, abandonment, or with broken family ties" (Brazil, 2012). As part of the Unified Social Assistance System (SUAS), the service's target users are "young adults and adults with disabilities in a situation of dependency, primarily those who

⁴ The Brazilian "Sistema Único de Saúde – SUS" has its origin with the Federal Constitution of 1988 in which the right to health is a fundamental right. Implemented by the Federal Law n.º 8080 from September 1990, it is free of costs public health care system.



receive the Continuous Cash Benefit (*BPC*)⁵, who cannot care for one self or be self-sufficient, do not have family support, and/or are in the process of deinstitutionalization from long-stay institutions" (Brazil, 2012, p. 4). The houses must have a maximum number of ten residents and be located in an urban area, facilitating access to essential services and promoting the autonomy of its users.

One cannot underestimate how vital such policies have been for the promotion of the deinstitutionalization process that has been taking place in Brazil since the late 1990s and early 2000s. However, such residential services have a very particular goal: to provide to those who no longer have family ties the opportunity to be reintegrated in a community, to be a participating member of society, and, in some cases, even try to bring them closer together with their families. They are services for people who live in social vulnerability or have been "abandoned" by family members. The idea that the "best place" for one to be is with their families is implied in the policy.

Nonetheless, there is a plea closely connected to the deinstitutionalization process that does not involve the issues of abandonment and previous institutionalization: the rights of people with disabilities to live with dignity and independently if they wish or if their families cannot physically, emotionally or financially provide the care they need. In such a context, to live without one's family is no longer a matter of abandonment but of different possible arrangements for one's life, an alternative mode of care. Hence there is a need for adequate housing spaces and services to accommodate such demand.

Although this is not a recent concern, it was only in 2015 with the promulgation of the Brazilian Law of Inclusion (Federal Law n.º 13.146⁶) that different living arrangements for people with disabilities were legally formalized. Besides naming several possible settings, the law also determines that public authorities must promote independent living policies. In reality, however, possibilities are a lot narrower. As previously stated, those who can count on a network of care usually live home with their families or in clinics. Many even live in nursing homes despite the legal prohibition for people who are under sixty to be residents in such facilities. The lack of living alternatives says a lot about how Brazilian society deals with disability.

That is precisely the point made by the group of mothers I have been working with since 2015. These women are strong advocates for the right of people with disabilities to live away from their parents, either as a way to develop independence and autonomy— even if an "assisted autonomy" – or as the result of family settings that make co-living impossible. Their plea is not always popular, resulting in several moral inferences on what is to be a "good mother and caregiver." The site where one lives is connected to preconceived ideas of what constitutes "good care" for people with disabilities and what is to be a "good family". Moreover, the issues my interlocutors face are not only linked to preconceived ideas regarding motherhood but are telling of how the experience of disability affects and is affected by expectations regarding the life course.

⁵ The *Benefício de Prestação Continuada* - known as BPC, is a social benefit first established in the Federal Constitution of 1988 with the first concrete policy being implemented in 1996. It grants the elderly and people with disabilities whose family income is no higher than a quarter of the minimum wage *per capita* a lifelong pension of the corresponding minimum wage per month. Between 2002 and 2014, 2.257.967 people with disabilities were beneficiaries of the *BPC* (Fonseca and Fietz, 2018).

⁶ Also known as the Statute of People with Disabilities (*Estatuto da Pessoa com Deficiência*), the federal legislation is the result of almost fifteen years of debate and is based on the UN Convention on the Rights for Persons with Disabilities. Its article 31 states that "the person with disability has the right to adequate housing, with one's natural or substitute family, one's partner, or by oneself, or in an independent living residence for people with disabilities, or still, in an inclusive residence."

Everyday Care Practices and Alternative Living Arrangements: The Constitution of a Movement

I first heard of the group through their *Facebook* page and soon scheduled an interview with Virginia⁷, the founder and organizer of the movement. In February 2015, she welcomed me into her apartment in a middle-class neighborhood of Porto Alegre for a recorded interview of almost two hours. After that, she invited me to join the group's meetings, arguing that the experiences shared by the participants would be helpful to my research. Virginia is a white woman with a graduate degree who has recently retired as a state employee. Her son Jose, who is now on his forties, has been diagnosed with both autism and bipolar disorder. Virginia has been his primary caregiver throughout his life. A trajectory that made her take on the "cause of care" as one of her main concerns, engaging with it both personally and professionally.

The meetings always take place in Virginia's apartment, and in 2015 when I started to attend them, they happened as often as twice a month. In the years that followed, the gatherings became less frequent. The average attendance was four or five people per meeting. Most of the participants are, like Virginia, middle-class white women who are the primary caregivers of their adult children with disabilities. As Virginia stated, throughout the years the group's interests could be sub-divided in three: 1) the actual construction and management of an assisted living facility; 2) the proposition of actions regarding the lack of proper legislation on the matter, and 3) to provide a space where caregivers can feel cared for and listened to.

For about two hours in the evening of a weekday, the women would gather to discuss the next steps towards strengthening a debate they consider to be a taboo in Brazil. Thus, they used their time to elaborate strategies to draw the attention of government officials, health and

social work professionals, and the population in general to the importance of assisted living facilities. A cause that, as they claim, addresses the wellbeing of both the person with disabilities and the families. During the meetings, the women also discussed strategies to implement such spaces, shared their experiences with places where their children had lived, and talked about current concerns and struggles. There was also time for Virginia to share stories of families from different parts of the country who contacted her with concerns about the future of their relative with a disability and asked for support in finding assisted living alternatives.

In every meeting, Virginia emphasizes that her main purpose is to care for family members of people with disabilities. Thus, the group must be a place where mothers feel embraced and share their experiences without feeling judged. As many women struggle to find time for themselves, Virginia makes sure to point out that if the mother is not well, she cannot properly care for their children. Her motto is: "who cares for the caregiver?" and she repeats it often, usually asserting that there is nothing selfish about wanting to feel good about oneself. She also stresses how policies do not consider the conditions of possibility of each household and do not take into consideration how hard it can be to provide care without support from the government. As she told me on our first interview, to people in general and to health professionals and policymakers, in particular, the mother

"[...] does not exist. No one sees the distress of a mother, so that's how it is. She can either die holding on to that or share the responsibility. That is if she has the money to pay for it. Or she dies. The burnout syndrome only exists in the department of health for professionals. It doesn't include the mothers. It doesn't exist for us. Mothers don't get sick. We can't feel exhausted."

Given this, the group aims its demands at State agents that, according to them, do not do enough on behalf of adults with disabilities. In this sense, they advocate for the creation of

⁷ Names were changed to preserve the privacy of my interlocutors.



specific legislation regarding private assisted living facilities. They also battle for state agencies to better regulate and control the few places that provide housing services which, they argue, are in a hospital-centric model. Another critical aspect of their claim is the cost of assisted living: they are aware that providing adequate care can be expensive and therefore think of public/private partnerships as the only way to provide adequate housing with a monthly fee that is not exorbitant. The group has calculated the approximate cost to maintain an assisted living house for ten people and came up with a value of five thousand Brazilian Reais (approximately USD 1.200,00) a month per person just to keep the house running without any profit. An amount they consider to be unfeasible⁸.

The lack of places these women consider to be adequate for their children to live does not change the fact that they are needed sometimes. On such occasions, the mothers look for the best place they can find and afford. Most of the women in the group are divorced or single and are both their children's primary caregivers and the family provider. Often overwhelmed and incapable of appropriately addressing the needs of their children, they seek alternatives despite the feeling of being constantly judged as a "bad mother" for not "wanting" to live with their children. Their exhaustion can be intense to the point that, as the mother of an autistic adult man told me, she felt relieved when her son was hospitalized with rigorous visiting hours. It was only then she could rest without being accused of being a "bad mother." Their experiences have shown that living with their children will not always be possible – or desired – hence the need for places where they can be adequately cared for and still live a life as autonomous and independent as possible.

There are also cases similar to that of Jose, Virginia's son. After a few years of living with his mother and having already lived in several clinics and homes, he decided to move to an

assisted living facility in a city by the ocean. This decision had direct implications for his mother's life, such as the loss of her reduced working hours⁹ and having to travel for almost two hours to visit her son. Nonetheless, Virginia praised her son's decision since she trusted the residence, and it was a place where he could exercise his autonomy by attending his daily activities at the nearby *Centro de Atendimento Psicossocial* by himself. Although less prominent than that of caregivers' exhaustion, the autonomy discourse is also present in their arguments for living arrangements other than with family members.

Jose's positive experience is very different from the many stories of places without infrastructure and with a large number of residents or, as Virginia puts it, small "insane asylums". The clinical model of most places that serve as a residence for people with disabilities makes them seem more like a hospital or an institution than a home. Besides, stories of neglect and violence are common in these places. I have often heard about places where their children were heavily medicated to be calmer or where situations were staged for visitation days. Virginia's engagement with the cause resulted from Jose's complaints about a place where he used to live. To make sure that such clinics cease to exist is one of her main goals. Mainly because she recognizes that as terrible as they might be, they sometimes end being the only resource for families that are emotionally, physically, or financially vulnerable. To make sure that her son and other people with disabilities do not have to be exposed to degrading and inhumane conditions and that caregivers can have peace of mind knowing that their children will be well even when they are not able to pro-

⁸ This number was based on research conducted in 2014 by the group and took into account the cost of renting a house, hiring adequate care workers, taxes, and bills such as electricity and water.

⁹ In Brazil, each state regulates the reduction of working hours for its employees, something that does not happen in the private sector. In Rio Grande do Sul State, the Right is regulated by State Law n. 13.320 from December 2009. It depends on proof provided by a state appointed doctor's evaluation that the worker is the primary caregiver of someone's who is dependent on their care. It can be renewed as many times as necessary, but the evaluation must be done every six months regardless of the condition that determines the dependence.

vide the care themselves became her lifelong cause.

Care, Family, and Living Arrangements

My interlocutors' concerns point to different aspects of the experience of disability as one moves through the life course. As their children reach adulthood, these women engage in new experiences that defy common sense expectations presented by motherhood. Their children are in an age when the daily responsibilities of a parent tend to diminish. However, this is not necessarily the case for parents of a person with cognitive disabilities when the ideal of a completely self-sufficient person is more explicitly challenged. More than thinking of their children as a burden or denying their capabilities, my interlocutors' plea draws attention to the struggles imposed by a society that is not prepared for modes of being that confront the liberal ideals of autonomy and independence. In such context, adults who do not fulfill expectations of independence and need the support of adequate facilities to live a life as autonomous as possible do not seem to matter.

As conflicting as it may seem when one considers the centrality that the ideal of autonomy and independence have in liberal societies, for people with cognitive disabilities to live away from home is still a stigmatized concept in Brazil. Partially due to the historical lack of state participation, which sowed the seeds for either family care or complete institutionalization with no middle ground. That is precisely the point raised by Virginia and her group. A group mostly composed of middle-class women whose children are now between the ages of twenty and fifty-years-old. The importance of intersectionality when thinking of race, class, gender, and disability has been the theme of discussions among disability studies scholars (Garland-Thomson, 1997; Ben-Moshe & Magaña, 2014). Although it is not the goal of this paper to address such specificities, it is essential to pay attention to another aspect that makes my interlocutors' experiences specific: generation.

The way disability is perceived has changed dramatically in the last few decades. Due to the

diligent work of activists and scholars who have been advocating in favor of the social model of disability since the 1980s and more recently with the UN Convention for the Rights of People with Disabilities (2006), the idea of disability as a relational category has gained force in Brazil. Although still far from the ideal, there seems to be a broader comprehension that the biggest challenge faced by those with any kind of impairments is the barriers imposed by society. In such a way that many actions have been taken to guarantee that segregationist models are extinct and to promote independent living and community participation. Nevertheless, there is a strong belief that the family will always provide the best care possible.

Raising their children with disabilities amidst all changes in legislation, policies, and the paradigms through which society relates to disability has a crucial impact on how my interlocutors deal with their role as mothers and caregivers. Even more so when they are also felling the physical impact of aging, having to deal with their own physical limitations as time goes by and start to need more care themselves. *Care* in this context is not only an emic term that is exhaustively used by them but also a category with methodological and analytical potential as both an entry point for addressing issues that are dear for those involved in care practices and a way to better understand the experience of disability in a given place (Drotbohm & Alber, 2015).

One cannot, however, talk about care and disability without emphasizing that it is a highly controversial term not only among scholars from the disability studies field but also within the social movement for people with disabilities. Those contrary to using this terminology understand that speaking of care infantilizes the person with disabilities, rendered as a dependable person who cannot make its own decisions or be responsible for one's own life (Shakespeare, 2014). Stressing that people with disabilities should not be seen as a burden, they propose to use terms such as support or help as less stigmatizing alternatives (idem). Still, for reasons that I hope to have made evident, I agree with feminist theories of



care scholars in their attempt to question the liberal ideals of autonomy and independence and constitute care as a central aspect of social justice (Kittay, 1999).

If one thinks of giving and receiving care as universal conditions, the negative connotations attached to it derive not from care itself but from the depreciation that “dependence work” or the work of care receives in liberal societies (Kittay, 2011). Thus, I think of care as a practice, something that must be done – or not done – to attend a specific need at a given moment (Mol, 2010; 2008). That is to say, as an “adequate response” that also depends on the expertise, skill, and sensibility of who provides it (Mol, 2008; Molinier, 2012; Aydos & Fietz; 2017). As a social and emotional practice, care “entails the capacity to make, shape, and be made by social bonds,” allowing it to be “perceived as a burden, but also as a pleasure or as a matter of course” (Drotbohm & Alber, 2015, p. 2). Foremost, care is also embedded in moral judgments.

Such characteristics help us to better understand the experience of Virginia and her group as mothers, activists, and caregivers. As they take part in the “anti-asylum” movement against “warehouses” where people are confined and isolated in inhumane conditions, these women have to defend themselves when accused of doing the very same thing they fight against: neglect and abandonment. There is a constant need to emphasize that looking for alternative living spaces for their children does not mean “bad care” or lack of love. A reality that is in sync with the idea of care as an “unfolding embodied and material process” that “depends not so much on a formula as a repertoire that allows situated action” (Law, 2010, p.67). As the coordination of different “goods” that must be taken into account when one reflects on what to do in a specific situation (Mol, 2008).

That is precisely the case in the experiences here presented. If in one hand we have the belief endorsed by public policies that the best place for one to be cared for is within the family, on the other we have the need for an “as-

sisted autonomy” that often involves physical strength, mental focus, time and energy from the caregiver. In the case of my interlocutors, it was not uncommon for their children to have fits of rage, need constant use of medication, or engage in leisure or therapeutically activities they cannot attend by themselves. There is also a fine line between preparing and encouraging their children to reach their full potential, raising “autonomous people” and the accusations of neglect, abandonment, and disregard. The way one balances all these needs is very much circumstantial.

Desire must also be considered. There are cases when the children no longer want to live with their parents or when the parents no longer wish to live with their children. A practice that is not uncommon and it is even encouraged when talking about non-disabled children, is often criticized when speaking of people with disabilities. Who should then have a say when it comes to this decision? Whose desire should prevail if not a mutual arrangement? As complex as these questions are – and I do not intend to provide an answer for them – I argue that the arrangements chosen must not be simply judged as a “bad parenting/good parenting” attitude.

Living with one’s family is not always the best nor the worst setting for those involved in the often-delicate care relationship between mothers and adult children with cognitive disabilities. Even though public policies continue to center the responsibility for the care of people with disabilities in the families – and especially the mothers -, my interlocutors are not always able to handle the many obligations imposed on them. Obligations made more demanding by a society where normality is imposed, and that is not prepared to deal with modes of being that defies its patterns. As they age, new situations and dynamics are presented, and new solutions and provisions must be sought. An experience that allows us to understand how disability is enacted in our society. In that sense, the claim for assisted living can also be understood as a quest of “good care”.

Conclusion

What I hope to have pointed out throughout this paper is how the claim for assisted living facilities enables a reflection on the experience of disability and its temporality in a given site. In a context where public policies have not yet accompanied the fact that people with disabilities and their caregivers are growing older, new demands such as the right to “live alone,” the concern with whom will provide the care, and the complex situation of many caregivers come to light.

Thus, to think of care work and to value it as such is central so that the experiences of Virginia and other mothers are not read through a lens that connects care to love and to the feminine. To consider it as practices that are acquired and perfected, that depend on the expertise, and that require time and dedication of those who are willing to undertake them allows us to better grasp the multiple layers of the mother-child relationship, especially one that is permeated by the experience of disability.

It is an effort to think of care as the multilayered term that it is and to consider the rights of caregivers and people with disabilities as constitutional parts of one another. A task that is directly connected to the recognition of care and dependence as constitutive parts of every and each human relationship (Kittay, 1999) even when it is made more visible in certain groups than others. I here contend that the claim for assisted living is a matter of social justice that addresses both the well-being and the rights of people with disabilities and the quest for adequate support for families and caregivers.

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