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The Work of Care

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By Helena Fietz

I have been conducting research on intellectual disability and care practices among families of diverse socioeconomic backgrounds in Porto Alegre, Brazil, since 2014.¹ Despite the many differences in family arrangements, class, race, and sociocultural background, most of my interlocutors share a common concern: “Who will care for my child once I am no longer able to do so?” As both mothers and children grow older, this concern becomes more urgent.

This question speaks to what I call, drawing from Alison Kafer’s (2013) work, temporalities of disability, or the ways that experiences of disability affect one’s relationship with time. In considering the care practices of these mothers, I argue that their experiences are also helpfully approached in terms of what Annemarie Mol (2008) calls “the logic of care,” because we are talking of an open-ended, interactive, and situated practice that is moral. This practice involves crafting new ways of living. Such temporalities not only affect the daily care practices of my interlocutors and the ways in which they relate to concepts such as adulthood and old age, but also shape the ways they manage hope and attempt to manage the future. To understand how, consider my first encounter with Anna.

I met Anna on a winter afternoon when I visited the school for adults with disabilities she had built from the ground up. A white middle-class widow, without any background in education, she decided to start a “school for special children” in her own garage forty-two years ago. Her aim was to guarantee that her son Paulo could have a place to learn, play and interact with other people, and to grant other people with disabilities the same opportunity.

As soon as I met her, Anna took me on a tour of the school, a large property owned by her and her husband. Crossing a big backyard, there was a classroom where two men and a girl—their only students at that time—were studying. At the other end, there was a big kitchen and a television room. In front of the house, by the door, her son was sitting in a wheelchair to grasp a patch of sun. He was accompanied by his paid caregiver, a tall black woman, one of the many professionals Anna hired as she became older.² Paulo greeted me with a head gesture and I

answered him in the same way.

As we walked back inside the house, Anna cheerfully told me that Paulo was now sixty-two years old and very healthy. His health made her proud, as she had always been his main caregiver. We then took an elevator to the second floor, still under construction. There was the biggest part of her project: The *Casa Lar* (Group Home) she dreams of building for people with disabilities, after realizing there was no such place in her hometown. Only after she completed this task, she told me, could she “die in peace.”

Anna said she was eighty-five years old. Being a widow for the past fourteen years, she had no fears except something happening to her before Paulo dies: “I pray that, if anything, we both die together so he is not here without me to take care of him. That is why I dream of building the house, so he can stay here, have a good place, even after I die.” She envisions a place for six adults to live and attend school at the same time. The living space would be on the upper floor, where there is a computer room, a music room, a living room and a gym space. The kitchen, the yard and the classroom would be downstairs, and for that reason she has put an elevator to help with mobility. There, they would be assisted by care-workers twenty-four hours a day. After forty years, the only thing left for her to build are the two bedrooms—one for the men and one for the women—which are essential for the materialization of her plan.

The experience of Anna and Paulo draws our attention to something I find central in the trajectories of other mothers with adult children with intellectual disability. When Anna and the women I encountered through my field work speak of the fear of death, they do not refer to an abstract concern. As the main caregivers of their intellectually disabled children, they have come to think of their own lives as intrinsically intertwined with those of their sons and daughters. Their deaths, in that sense, would mean the abandonment of those they care for. This is a common concern among most mothers of young children with intellectual disability, and it can become a never-ending fear which worsens as both they and their children age.

I argue that this fear of dying and aging is connected to how we understand disability in the present since, as stated by Kafer (2013, 19), it “determines how one imagines disability in the future.” In a world where able-mindedness and able-bodiedness are the norm, disability can only be represented as something to be avoided at any cost, as is the task of caring for those often considered to be most dependent. The Brazilian state has never effectively taken responsibility for dependent family members. Caring for people with intellectual disability was always and indeed still is perceived as a family responsibility (Fonseca and Fietz 2018).³ Since the work of care is mainly undertaken by women, it is

ultimately the mother's responsibility to provide ongoing, quality care for their offspring until they are able to fend for themselves, regardless of whether they have state support or not.

As mothers of adults, my interlocutors faced a near-total lack of public services or support for their children as they grew-up. Their task of preparing their sons and daughters for the world, while also trying to shape a world that would accept them, to use Kittay's terms (2010), was strenuous. They had to locate the scarce available services either through governmental channels or networks of knowledge built through other parents and professionals. In this sense, the work of caring depended on creating the means to do so. In fact, many of the institutions that provide activities and services for people with intellectual disabilities in Brazil were founded by parents as early as in the 1950s. The work of engaged families, in alliance with professionals and activists, has been slowly changing the narratives of disability and the landscape of public policies in Brazil, especially since the early 2000s. This change is shaped both by what is considered the private realm of domestic life and by the public debates on the matter (Rapp and Ginsburg 2001).

In recent years the number of parents interested in assisted living alternatives has increased. Like Anna, many of them work towards building homes from the ground, in processes similar to what James Holston (1991), referring to the building of houses in the outskirts of Brazilian cities in the late 1980s, called *autoconstruction*. Regarding the specificities of each context, much like the working-class families Holston observed, these parents perceive the new living arrangements as a way to change the present conditions of their children's life while also addressing past experiences and imagined futures. This is an endeavor through which they reshape many of their own assumptions about what it is to be well-cared for and to live a life to its fullest, challenging the notion that no one can provide better care than the family. It is also a work of destigmatizing alternative living arrangements—often perceived as abandonment—and of committing to new possible futures.

With this complex autoconstructive work, Anna aims to produce new ways for adults with intellectual disabilities to inhabit a world that is not yet prepared for diverse modes of being. This task is motivated by her fear of aging and dying before envisioning alternative networks of care for her son. In that sense, reimagining living arrangements for adult children becomes a practice of hope, or the work of actively creating spaces, building networks and pursuing acceptance (Mattingly 2015). As a work of care, this autoconstruction is a continuous, specific and manageable process that is done in practice. Within all the contradictions that the work of care entails, mothers like Anna share the hope that the world can be a less hostile place for them and their children.

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Notes

1) This study was financed in part by the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior – Brasil (CAPES) – Finance Code 001.

2) Historically in Brazil, in a context of a lack of care policies, middle-class and rich families counted on the domestic labor of working-class women to care for their infants, elderly or disabled. As most of these care workers are black women, race cannot be disregarded in analyses of care in the Brazilian context (Engel and Pereira 2015).

3) Although institutionalization was never the main policy for people with intellectual with disabilities in Brazil (Block 2007), the country has a long history of institutionalizing people with disabilities and mental health issues. Since the early 2000s, a deinstitutionalization process has been put into practice and gained force with the promulgation of the Federal Law 10.216/2001. For disability in the Brazilian context see also Lopes 2014; Aydos 2016; Mello, Block and Nuernberg 2016; Gavério 2017.

[Helena Fietz](#) is a Ph.D. Candidate in the Department of Anthropology at Universidade Federal do Rio Grande do Sul/UFRGS, Brazil. Her dissertation explores care practices for adults with intellectual disabilities in Brazil, focusing on the ways that the experience of disability shapes and is shaped by family relationships, public policies, and notions of what constitutes "good care" within a given socio-historical context.

["Disability from the South: Toward a Lexicon"](#) is a series edited by Michele Friedner and Tyler Zoanni. Contributors in this series consider what

changes in theorizations of disability when research is located in places marked "Southern" and offer reconfigurations of keywords and concepts typically utilized in the study of disability.

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