

INTIMATE CONNECTIONS AND SINGULAR EMBODIMENTS: DISABILITY IN TIMES OF THE COVID-19 PANDEMIC (*)

Helena Fietz^(**), Anahí Guedes de Mello^(***) and Claudia Fonseca^(****)

When COVID-19 broke out in Brazil, most state governors and city mayors followed World Health Organization (WHO) guidelines and, in defiance of federal government protocol, adopted policies of social isolation and distancing. To stay home with our families, going out only when necessary is an effective policy for care and prevention aimed at the “general population.” Still, when approaching practices of care from the standpoint of feminist ethics (Puig de la Bellacasa, 2017), one should be wary of preconceived norms based on universal principles and reflect on the singularities of specific situations. Thus, a few questions guide our analyses: how do these “universal” guidelines affect specific social groups? In particular, how do they affect people with disabilities who are part of the so-called “risk group”?

Many people with disabilities spend their lives worrying about viral or bacterial contamination, which can be fatal for them. Hence, many sanitary routines that are now widely practiced to avoid contagion by COVID-19 – the obsessive washing of hands; the use of masks; the cleaning of spaces, objects, and various prosthetic devices such as wheelchairs, walkers, and canes – were already part of their care routines long before the pandemic. If anything, COVID-19, given the new risks, has only made their precaution more urgent. However, these routines have gained in visibility, thanks to the fact that non-disabled bodies are now also required to perform them. They are no longer a matter of individual responsibility, but of public health.

On the other hand, for people with the kind of disability that requires them to lean on objects and feel out spaces to gather information and move about in the world, it is practically impossible to follow the World Health recommendations to the letter. The recommended policy of distancing oneself from any potentially infected objects requires these people to invent new body techniques. For example, Marina, a young woman with cerebral palsy, tells us how a simple walk is more distressful than ever in this moment:

“I don’t use assistive technology. But when I go do groceries, for example, I’ve become terrified of stumbling,

of holding on to things for support, or even of falling. More than ever, I do everything in slow motion, always fearful lest something happen. And of course, I have to take care not to damage my mental health with all this worry...” (Marina)

Beyond assistive technologies and new body techniques, for many people with disabilities, the biggest challenge in this era of COVID-19 is the articulation of their support network. Theories of care stress how we are all interconnected, how the ideal of autonomy can be an illusion that leads us to ignore the actors involved in the infrastructural networks that support our existence. Precisely because it threatens to cut these networks, the policy of social distancing forces us to become aware of how much we depend on others. This awareness, once more, hits people with disabilities hardest.

The physical proximity involved in care relationships, particularly for those who depend on someone to perform daily life-supporting activities such as eating, dressing, or bathing, complicates the prescribed preventive measures. As a result, the normally invisible labor of this support network – including family members, neighbors, health workers, and other public agents – emerges from the shadow, now representing the threat of contagion, exacerbated by the precarious conditions in which many Brazilians live.

Perhaps one of the greatest challenges for Brazil’s policymakers is to forge social distancing strategies adapted to the living conditions of lower-income neighborhoods (favelas) and territorial occupations where we often find large families (some including three- and four-generation families) living in a few square meters. We can cite the example of Lisa, a 6-year-old girl born with a severe neurological disability and who lives on the outskirts of Porto Alegre, in a three-room house with her parents and five siblings. Lisa does not speak and until last year, when she turned 5, depended on a ventilator to breath. Before COVID-19, health professionals, including physical therapists and health agents, visited the family regularly to check on her and to provide treatment. Now, in the face of increasingly restricted health services, she has come to depend almost exclusively on her



family. This new configuration implies a rotation of engaged caregivers who, given the loss of income caused by the pandemic, are forced to leave the house daily, circulating through possibly contaminated areas, looking for ways to support the family.

Entangled in a network of interdependencies that require bodily proximity, Lisa's care presents particular challenges. Her example underlines the need for any policy of social isolation to adjust to the specificity of these bodies, providing ways to, at the same time, prevent the disease and ensure the continuity of adequate care practices.

Another important point that has yet to be properly addressed by the Brazilian media is the situation in collective institutions for people with disabilities. The experience of other countries shows that the vulnerability of people living in group homes and assisted living facilities is appalling. According to a recent report,⁽¹⁾ residents in homes for the disabled and other similar facilities in and around New York are 5.34 and 4.86 times more likely to develop COVID-19 and die from the virus respectively than the general population. A probability that, even representing the way in which some populations are "left to die," is understood by many as inevitable. It is no surprise that the father of a young man with cognitive impairment, upon hearing of the death of his son's roommate, exclaimed: "If it is the virus, what the hell are we going to do?"⁽²⁾ However, we must ask whether it is the virulence of the disease in this "at-risk population" that condemns so many residents and employees to a high mortality rate, or if the responsibility does not fall on the extremely precarious conditions of these homes.

At first, several European countries computed the death rate caused by COVID-19 only from patients who died in hospitals, simply ignoring deaths in nursing homes. This is worrying, especially in the Brazilian context, in which we have little information on such places. The little we know only exacerbates our concerns: tales of crowded institutions, a shortage of professionals, caregivers without specialized training working with scarce resources, and no protective equipment (such as gloves, masks or alcohol gel). In one case, employees were reported to have improvised face masks from hair caps normally used in the kitchen.

To conclude, let us evoke once again the many care practices that, despite being essential for everyone during pandemic times, are often completely overlooked in generalized public policies. WHO recommendations are central to protecting everyone's lives, especially those most vulnerable to COVID-19. Still, as Catalina Devandas, the United Nations rapporteur for disability issues points out, it is urgent that people with disabilities have the assurance of knowing that their survival is a priority.⁽³⁾ Thus, for broad public policies to be truly effective, they must account for the singularities of specific forms of embodiment as well as the social and cultural contexts in which they are enacted. No experience should be excluded a priori from the global health policies

designed to protect the population. Thinking with care presumes looking at contexts that include different people and families, many of whose living conditions are not easily adapted to social distancing. COVID-19 puts us face to face with unanswered questions and unpredictable outcomes, and forces us to live in a situation of constant tension and open-ended futures that render reflections and discussions on care practices ever more urgent.

Notes

(*) This piece was first published in Portuguese on June 12, 2020, in the [ANPOCS – National Association of Post-Graduation and Research in Social Sciences' series Ciências Sociais e Coronavirus issue 61](#). A first English version appeared at [Somatosphere](#). Authors thank their colleagues from the Group for Studies on Anthropology and Disability of the Federal University of Rio Grande do Sul for the discussions and contributions to this piece.

(**) Ph.D. Candidate in Anthropology at Federal University of Rio Grande do Sul, in Porto Alegre, Brazil. Member of Grupo de Estudos em Antropologia e Deficiência, Grupo de Pesquisa Ciências na Vida, and the Brazilian Association of Anthropology Committee on Disability and Accessibility.

(***) Ph.D. in Social Anthropology, Federal University of Santa Catarina. Researcher at the Center for Disability Studies, UFSC's Department of Psychology, and Associate Researcher at Anis – Institute of Bioethics, based in Brasília, Brazil. Coordinator of the Brazilian Association of Anthropology Committee on Disability and Accessibility.

(****) Professor of Anthropology at Federal University of Rio Grande do Sul, in Porto Alegre, Brazil. Member of Grupo de Estudos em Antropologia e Deficiência and of Grupo de Pesquisa Ciências na Vida.

(1) New York Times, April 17, 2020. Available at: <https://www.nytimes.com/2020/04/08/nyregion/coronavirus-disabilities-group-homes.html>.

(2) See <https://www.nytimes.com/2020/04/08/nyregion/coronavirus-disabilities-group-homes.html>.

(3) See <https://reliefweb.int/report/world/COVID-19-who-protecting-people-disabilities-un-rights-expert>.

Reference

Puig de la Bella Casa, M. *Matters of Care: Speculative Ethics in More than Human Worlds*. Minneapolis: University of Minnesota Press, 2017.

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