

HABILITATING BODYMINDS, CARING FOR POTENTIAL: Disability Therapeutics after Zika in Bahia, Brazil

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I arrived at Sara's home after a long, hot bus journey from my apartment in Salvador da Bahia, Brazil, in October 2017. She was living in Águas Claras, a *periferia* (low-income periphery neighborhood) located near the outskirts of Salvador, with her husband Leonardo and their daughter Lizinha, who was then going on two years old.¹ Lizinha was one of the first Bahian children born with congenital Zika syndrome (CZS).

The shiny white tiled floor of their small living room contrasted jarringly with the humble exterior of their auto-constructed home, borrowed from a cousin who was working in São Paulo. Against one wall, brightly colored toys rested in bins. Lizinha lay on her tummy on a foam mat when Sara led me through the door at the top of the brick stairs. When she heard us come in, the little girl raised her head a few inches above the floor, responding to our voices and approaching footsteps. But neurological damage from Zika had weakened her cervical spine control, so she didn't lift her head and turn around like a "typical" two-year-old might do. As we settled in for our interview on the beige couch separating the living room from the kitchen, Sara picked up Lizinha and held her on her lap. Lizinha squealed with delight, breaking into a big smile that exposed her emerging first teeth.

“You know she’s going to die, right? It may not be tomorrow, but she’s going to die.” This was what doctors had told Sara and her husband when she and Lizinha were in the hospital after delivery. The physicians warned that the extent of their infant daughter’s neurological damage made her a lost cause. As long as she did live, the doctors said, she would be like a “hollow trunk” (*um tronco vazio*), with almost no brain function at all. This dire prediction may have been meant to brace Lizinha’s parents for the worst, but Sara considered it an insensitive affront to their hopes for their little girl.

Lizinha did not die, and since she was born, Sara has been determined to aid her disabled daughter’s development as much as possible. She explained that Lizinha was on a ketogenic diet—a high-fat, low-carb diet that may prove useful in controlling epileptic seizures. Like many of the children born with CZS, Lizinha used to have frequent seizures that, besides being dangerous in themselves, held back her developmental progress by “shocking” her neurological system into relative disarray. Hard-won skills like following objects with the eyes or holding up the head just an inch higher could be “forgotten” in an instant and had to be re-learned, so controlling Lizinha’s seizures was vital to protect her brain function and developmental progress. Meals for the pediatric ketogenic diet must be individually homemade, measuring out the exact amounts of each ingredient to the decimal point—a tedious and intensely laborious undertaking. Additionally, the family had just won a legal injunction to import CBD oil from the United States, also to help control their daughter’s seizures. When she wasn’t accompanying Lizinha to her numerous therapy sessions, Sara spent significant time at home reinforcing the exercises done there: encouraging her tiny hands, usually balled into fists, to open and feel toys with various textures; moving objects across and around her line of sight so she might follow them with her eyes; talking to her to stimulate auditory processing and speech.

At one point in the interview, Sara motioned to the kitchen counter, on which sat a large bottle of a nutritional supplement called Speak+d Smooth[®], which sold for around R\$400 (US\$150 at the time). She explained that it was “an Omega-3 [supplement] imported from the United States,” originally formulated to aid speech development in autistic children. Lizinha’s pediatric neurologist had said it would bring “marvelous results,” making the little girl’s speech take “a leap forward.”

All of this also required significant financial investments on the family’s part. Sara and Leonardo had moved to Salvador from the semi-rural interior of Bahia, and while they are both white, they belong to Brazil’s precarious “new middle

class”—not poor enough to be counted among the very poorest, but far from economically privileged (Klein, Mitchell, and Junge 2018). Leonardo worked intermittently in construction when he could find work. And, like many other moms I know, Sara had given up her job as a clothing store sales attendant to care for Lizinha full time. The couple made sacrifices to pay for the diverse collection of substances and technologies understood to aid in the little girl’s development. For Sara, it was well worth it to know they were doing all they could to ensure Lizinha reached her full potential. She told me: “We’re always trying things out, and Lizinha is going to be progressing [*indo na frente*], right, Lizinha? . . . Thanks to God, it’s getting results!”

This article began in Sara’s living room. While it wasn’t the first time I had been struck by a parent’s considerable investment in their Zika-affected child’s development, it was there I began to think of the disabled child bodymind as a site of aspiration—both discursively, as a site of meaning production, and materially, as a fleshy locus where aspirations to child development were being quite literally embodied. I was both intrigued by and uncomfortable with these intervention-heavy forms of care. By investing so much time, money, and labor in the habilitation of their children, were parents not cleaving to the idea that the more typical or “normate” (Garland-Thomson 1997) their children could become, the better? In aspiring to augment their children’s bodymind capacities to the maximum possible, were they not participating in and perpetuating ableism? This article grapples with these questions, attempting to understand the stakes of habilitative therapies from parents’ perspectives in a way that does not reduce their aspirations for their disabled children to “a failure to grasp the politics of their own situation” (Gammeltoft 2008, 826). In what follows, I trace how mothers raising children with congenital Zika syndrome cultivate their children’s bodyminds through what I refer to as *habilitative care*: care involving a range of substances, technologies, and techniques understood to encourage maximum potential development of embodied abilities in young disabled children.

I dwell on habilitative care to reflect on the stakes of what is done or not done to young disabled bodyminds in the name of “potential.” While anthropologists have explored habilitation in the context of cochlear implantation, I dwell on a wider range of technologies and practices mobilized in disabled children’s habilitative therapies, linking them under the umbrella of *habilitative care* (Friedner 2022). I also attend to the stakes of habilitative care for families living in precarity, not just neurological (Mauldin 2016) but also socioeconomic. I argue that Bahian mothers’ intensive investments in habilitative care as a bodymind-potentializing

practice constitute a way of asserting their children's personhood by contesting narratives of their children's lack of futurity—narratives shot through with exclusionary ideas about which lives are worth living and whose bodyminds are worth investing in to bring out their full potential. I use my ethnography in Bahia to unsettle critiques of (re)habilitation as medicalized ableism, asking how we might attend to the shaping of developing bodyminds amid the precarities of everyday life in parts of the Global South where the future of marginalized bodies especially is itself made precarious (Grech 2015; Grech and Soldatic 2016).

ZIKA AND ITS AFTERLIFE IN BAHIA

Since 2016, I have worked with families raising children diagnosed with CZS in northeastern Brazil, the global epicenter of the 2015-2016 Zika virus epidemic. This ongoing, longitudinal research focuses on the long-term socio-corporeal impacts of Zika in Salvador, Bahia, asking how Bahian families living with the virus' embodied fallout reimagine their lives in the wake of the epidemic and care for children with multiple disabilities in the context of Brazil's recent economic, political, and public health crises.

In late 2015, doctors in Northeast Brazil noticed a sharp increase in the number of fetuses and babies with congenital neurological malformations, most notably microcephaly (reduced cranial circumference due to incomplete brain development in utero). Clinicians and scientists quickly linked these abnormalities to the Zika virus, a vector-borne disease first detected in Brazil earlier that year (Diniz 2017). Transmitted by mosquitoes as well as sexually, in pregnant people Zika can pass through the placental barrier and infect the fetus, disrupting the development of fetal brain cells. The virus attacks the central nervous system, so microcephaly is only one of the many manifestations of what is now called congenital Zika syndrome, or CZS. Babies born with CZS may have microcephaly, calcifications in the cerebral subcortex (the area of the brain responsible for motor control and skills learning), arthrogryposis (joint curvature), ocular damage (leading to low vision), and hypertonia (rigid muscles causing mobility difficulties). Some children may also have cerebral palsy (a neurological condition that affects a person's ability to move, maintain posture, and balance), and many have epilepsy (CDC, n.d.).

Zika primarily impacted the Northeast region of Brazil, and those who gave birth to children with CZS were by and large women of color in low-income communities in urban areas and the interior. The *Aedes aegypti* mosquito, largely responsible for virus transmission, can breed practically anywhere there is standing water, but certain environmental and infrastructural conditions commonly found

in impoverished areas can provide an especially favorable setting for mosquito proliferation. Combined with a lack of access to comprehensive reproductive health care, including safe and legal abortion, this meant that Brazil's most marginalized were also the most exposed to Zika and its long-term consequences (Cruz et al. 2023; Diniz 2017). Between 2015 and 2022, Brazil reported 1,857 confirmed cases of CZS nationally, and the state of Bahia had the highest number of cases in the country after Pernambuco.²

I spent four years in Bahia between 2015 and 2019. In 2016 I began volunteering with the local parents' support group-turned-NGO, Associação Abraço a Microcefalia (I Embrace Microcephaly Association). I did clerical work; helped organize regular gatherings; played with children while parents participated in events; stocked donated goods; and translated grant proposals to capture funds for the fledgling NGO. I also conducted fieldwork at Cepred, the state-run rehabilitation center that enrolled many of the children into its early intervention program, where I interviewed fifteen parents and three therapists and observed children's therapy sessions. I also accompanied parents and children to informational sessions on CBD oil for epilepsy; observed health worker trainings; joined parents in disability rights direct actions; and participated in parents' WhatsApp message groups. Since 2019 I have kept in touch with my interlocutors via WhatsApp and other social media and conducted five-year follow-up interviews with parents via Zoom. This article is based primarily on formal interviews and participant observation between 2016 and 2019.

Brazil's first colonial capital, Salvador, is majority Black and home to a vibrant African diasporic culture. Precarity in the city is classed, gendered, and racialized: *periferias* are home to primarily Black and Brown families, while those living in high-rise condominiums in wealthier areas are generally white or lighter-skinned. Sara is a rare exception. Bahia has markedly poorer maternal and infant health indicators compared to the wealthier states in the South and Southeast, a legacy of the country's colonial history and unequal economic development. With their sprawling districts of informal housing and precarious sewage and water infrastructure, the *periferias* of Salvador also constitute a prime location for mosquito proliferation and, in turn, for the spread of Zika. In *periferias*, women are often heads of household and primary or sole caregivers for children. With fathers frequently absent or taking little part in childcare, women bear this responsibility while balancing economic instability. Austerity measures approved during the recent Temer and Bolsonaro governments threaten the social assistance stipends that allow many mothers to feed their families, and finding work to earn extra

money proves difficult, especially for mothers of children who need specialized care nearly 24/7.

The Zika epidemic unfolded during a turbulent time in Brazil: an economic recession bloomed into full-fledged crisis, former president Dilma Rousseff was ousted by a parliamentary coup, and her successor proceeded to approve a series of draconian austerity measures. Most drastically, Constitutional Amendment 95 froze public spending on health care, education, and social assistance programs until 2036.³ Dubbed the “Constitutional Amendment of Death” by the opposition, this measure all but guarantees that those relying on government-funded services—including those living with Zika’s consequences—will continue to fall deeper into precarity. Combined with rapid inflation during the Bolsonaro administration, 2 million Brazilians have fallen into extreme poverty (Madeiro 2021). During the first years of their children’s lives, most mothers in my research relied primarily, if not solely, on Brazil’s public health system, the Sistema Único de Saúde (SUS), which is free at point of service. Many also relied on the Benefício de Prestação Continuada, or BPC, the government pension designated for disabled people or their caregivers. The BPC provides families with the equivalent of one minimum monthly salary (*salário mínimo*), which many complained was not nearly enough to cover household expenses, but it nevertheless helped mothers who were dedicating all their time to their children (in fact, receiving the BPC disqualifies one from formal employment).⁴ Very few families were able to afford private health plans that granted their children access to a wider range of therapy options, and some patched together SUS and lower-cost private health plans, striving to give their children the best care possible. Regardless of each family’s particular arrangements, with regressive policies tearing at the threads of what little safety net they still have, and with the acceleration of a long-standing neoliberal project of dismantling public health care and social supports, the Bahian mothers in my research found themselves looking into a hazy future.

Early in the Zika crisis, some doctors told new mothers like Sara that their babies wouldn’t survive, or that if they did, they would essentially be “vegetables.” Others publicly referred to Zika-affected babies as a “lost generation,” implying that their disabilities would make them unable to participate in or contribute to society in any meaningful way (Mello 2016). However, as I will show, mothers invest time, money, and concentrated effort in their young children’s development, thereby countering these narratives of non-futurity. Through habilitative care, they enact their children’s future potential through the cultivation of their small, developing bodyminds.

HABILITATING BODYMINDS, CARING FOR POTENTIAL

I speak of children’s “bodyminds” here for two reasons. First, the varied therapeutic practices I am addressing take for granted that “body” and “mind” are inextricable from one another. Habilitative therapies are premised on the wisdom that “mental and physical processes not only affect each other but also give rise to each other” (Price 2015, 269). When Lizinha hears her mother speaking to her (physically senses soundwaves through her body’s aural mechanisms), her synapses fire, neural pathways are created or reinforced, and these in turn shape the sounds she herself makes, as well as her overall mood. Lizinha broke into a wide-mouthed smile every time Sara spoke to her during our interview, expressing her pleasure and joy. As for many other children with similar conditions, when she was feeling irritated or tired, therapy sessions tended to lose their effectiveness and sometimes were cut short. Building on Margaret Price’s work, Sami Schalk (2018) proposes that the concept of *bodyminds* can also help us theorize the embodied impacts of other forms of oppression and social marginalization, such as structural racism. This is important for me here because most of the children and parents in my research are Black, Brown, and/or low-income, thus also living within the constraints of structural racism and economic inequality. Their bodymind capacities, actual and potential, are affected by the access they have to habilitative therapies and equipment, medications, and other forms of intervention. Because access to these resources is unequally distributed along class and racial lines, children embody these forms of inequality in particular ways. To habilitate always means to habilitate bodyminds.

Habilitation aims to help young disabled children develop embodied skills and capacities, such as hand-eye coordination, the ability to chew and swallow foods, and verbal communication. This differs from *re-habilitation*, for the objective is not a return to a prior state of ability or skill now lost, but rather the training of *new* skills (Friedner 2022; Mauldin 2016). Habilitation “is predicated on the potential, because of plasticity, we have to shape the inner workings of the brain” (Mauldin 2014, 132), making habilitative caregiving always also a practice of imagining, and indeed *enacting*, what should or could be possible for a child in the future. The expanding availability of cochlear implantation (CI) technology is changing expectations for deaf and hearing-impaired children, “unleash[ing] the potentiality of hearing brains and produc[ing] ‘wonderful outcomes,’” such that the widespread expectation is that these children can “become ‘normal’” (Friedner 2022, 126). Yet, as Michele Friedner points out, the opening of this potential to create normatively hearing and speaking subjects at the same time closes down other

possibilities of deaf sociality, since anything but normative hearing is increasingly perceived as not just undesirable but avoidable (see also [Friedner 2022](#)). Friedner, Laura Mauldin, and many others have noted that the work of habilitative care is eminently gendered: women around the world—and particularly mothers—shoulder the responsibility to aid their children in reaching their potential. This also holds true in Brazil. [Friedner \(2022\)](#) also highlights the precarity of habilitation technology in India, as poorer families struggle to keep up the expensive maintenance of CI devices after initial implantation. I wish to highlight similar conditions of precarity and gendered care labor in Bahia, where many mothers of children affected by congenital Zika syndrome struggle to make ends meet, let alone consistently access costly habilitation technologies.

Anthropologists have attended to the ways in which notions of plasticity shape bodily practices in Brazil, from popular and religious healing to biomedicine, Indigenous and Afro-Brazilian ceremonies to cosmetic plastic surgery ([Béhague 2016](#); [Edmonds 2010](#); [Jarrín 2017](#); [Rabelo 2014](#); [Sanabria 2016](#); [Vilaça 2005](#); [Williamson 2021](#)). While some have emphasized how biomedical therapeutic technologies like disaggregated, synthetic birth-control hormones, become modalities of self-care, bodymind enhancement, and even social mobility, scant attention has been paid to technologies of (re)habilitation for children, much less for disabled children (cf. [Béhague 2016](#); [Béhague and Lézé 2015](#)). These scholars have nevertheless shown that therapeutic interventions of various kinds are inextricable from social imaginaries of optimal embodied capacity and aspirations to social mobility, entangled with pharmaceutical and other medical markets, and profoundly shaped by Brazil's history (including its eugenics history) of shaping bodies and populations toward particular ends. Aspirations cutting across class and race—to beauty, social mobility, modernity, wellness, whiteness, and, I submit, children's future potential—are realized in and through the quite literal molding of flesh.

After the initial chaos of the Zika outbreak, health authorities began turning their attention to affected children's longer-term needs. The Brazilian Ministry of Health published a set of guidelines for the clinical care of children diagnosed with CZS, which emphasize the vital importance of early intervention (*intervenção precoce*) for children born with impairments—usually a combination of physical, occupational, and speech therapy designed to aid the development of embodied abilities in children diagnosed with developmental “delays.” This early period—according to child development and neurological sciences, the time of the brain's greatest plasticity ([Béhague and Lézé 2015](#), 251; [Goldfarb 2015](#); [Rose and Abi-Rached 2013](#), 15)—therefore proves critical. From birth until three years

of age, the Brazilian Ministry of Health recommends that children born with impairments be placed in early intervention programs to encourage “the best possible development.” The first three years of life constitute “the phase in which the brain develops the fastest, constituting a window of opportunities for the establishment of the functions that will lead to good health and optimal productivity in the future” (Ministério da Saúde do Brasil 2016, 9–10). These guidelines hew closely to global health discourses: UNICEF (n.d.) similarly alerts that for all children, “in the brain-building process, neural connections are shaped by genes and life experiences—namely good nutrition, protection and stimulation from talk, play and responsive attention from caregivers. This combination of nature and nurture establishes the foundation of a child’s future.” For children with disabilities, UNICEF affirms, focused intervention is even more vital.

As elsewhere in the world, with the brief window of time for maximum neural plasticity, young disabled children are swept up in a race to reap the maximum possible benefit from therapies while they are still very young and neurologically most malleable. And so, soon after their diagnoses, Bahian children were funneled into the early intervention program at the state-run rehabilitation center (Cepred). There, rotating teams of therapists worked with children in thirty-minute sessions several times a week, and parents learned how to do stimulation exercises with their children at home to encourage motor, sensory, and cognitive development. Indeed, clinicians stressed repeatedly that parents must reinforce these exercises at home to reap the maximum benefit of therapy. Habilitative techniques and technologies, therefore, make their way far beyond the clinic. And when they do, they are primarily, if not solely, the domain of mothers, the ones who perform the vast majority of caregiving for children, habilitative and otherwise, throughout Brazil.

Histories of Habilitation

Since the nineteenth century, disabled Brazilian children have been targeted for various kinds of therapeutic intervention. At the turn of the twentieth century, eugenic nation-building projects sought to perfect the Brazilian “race” and populate the territory with people deemed “fit,” making “modern therapeutic and hygienic resources” a priority for “defective” children (Lobo 2009, 322). In large part, the importance of such intervention was framed as an investment in the country’s future, since advocates argued that in the long term, disabled children would become not just unproductive citizens but financial burdens on the state (Lobo 2009, 374). Labeling CZS children a “lost generation” today echoes this kind of thinking.

Segregation and the institutionalization of disabled people was never the norm in Brazil. Instead, the country emphasized “medical pedagogy” (a kind of proto–special education) in psychiatric hospitals, and puericulture, “the scientific cultivation of the child” (Block 2007; Stepan 1991, 77). Intervening as early as possible became key. Mothers have therefore played a central role in efforts to cultivate future citizens and, by doing so, help modernize the nation (Martins and Freire 2018; Otovo 2016). Eugenicist organizations like the Brazilian Mental Hygiene League sought to “intervene in the family and in the child” to facilitate “the discovery of defects, anomalies and physical illnesses that must be *without delay* corrected and cured” and “organize the discovery and education of the mentally deficient” (physician and educator José Paranhos Fontenelle, quoted in Lobo 2009, 116; my translation and emphasis). This urgency again came to the fore in the 1930s and 1940s, when the populist dictator Getúlio Vargas declared “the protection and health of children” as of utmost national importance, calling on governors throughout the nation to turn their attention to improving the health of the citizenry through maternal and child health interventions (quoted in Otovo 2016, 4).

Mid-century, as urban industrialization got underway, preventing or ameliorating “mental or physical deformity” in children became an eminently economic question for Brazil’s leaders, and successive outbreaks of poliomyelitis led to the creation of rehabilitation services in large cities (Brégain 2022, 372; see also Souza and Mancussi e Faro 2011, 299). The rehabilitation of children was presented as “a cost-effective investment for the nation, since it allowed an increase in national production, savings in disability pensions and the recovery of social [security] contributions” (Brégain 2022, 368). Advocates cast habilitating disabled children to their maximum potential as urgent largely because the nascent nation needed “productive” citizens. This thinking hasn’t disappeared; one mother, when I asked what she envisioned for her then two-year-old son in the future, said she hoped he would become a “good worker,” even if disabled.

While many traces of eugenics thinking remain, dominant approaches to childhood cognitive disability in Brazil today owe themselves largely to the work of developmental psychologist Helena Antipoff (1892–1974), who believed steadfastly in intellectually disabled children’s potential to learn and participate fully in society. Going against some eugenics thinkers who claimed that people’s “innate” abilities could not be modified, Antipoff brought disabled and nondisabled children together in classrooms, insisting on disabled children’s potential to learn and grow in community with others (Block 2007). That her approach to intellectual disability has become so central to pedagogical models in Brazil today—in both

prominent non-profit organizations and governmental inclusive education guidelines—speaks to a continued emphasis on the malleability and adaptability of children’s bodyminds.

Pediatric rehabilitation boomed in the latter half of the twentieth century with the consolidation of the physical therapy profession and founding of pediatric rehabilitation institutes (Fietz 2020; Souza and Mancussi e Faro 2011). Marco Gavério and Gil Lourenção (2020, 156; my translation) contend that since this period, perhaps due to the influence of cybernetics, approaches to rehabilitation have shifted from models of “correction” and the restoration of function to models of “capacitation” (as in improvement or recovery) and, more recently, to the “robotization/mechanization” of bodies. With these shifts, they argue, rehabilitation no longer so much concerns attaining a standardized “normal” as it does maximizing individual capacities. While normative horizons of bodymind ability continue to animate rehabilitation, emphasis is placed on personalized therapeutic interventions that consider each patient’s particularities (Gavério and Lourenção 2020, 157). I suggest we can also see this emphasis in early childhood habilitation, in the work of therapeutically potentializing these very young bodyminds, both in and beyond the clinic.

Such shifts haven’t made the project of habilitating disabled children any less urgent, and further developments at the turn of the twenty-first century have only magnified this urgency. The 1990s and 2000s were both a period of consolidation of social rights for Brazilian citizens, including disabled people, and a period of an international explosion of brain research (Costa, Silva, and Jacobsen 2019; Rose and Abi-Rached 2013). This research highlighted the brain’s plasticity, particularly in the beginning of life, and ushered in global and national guidelines for intervening early and intensively to ensure maximum potential child development, as discussed above.

Whether it’s fixing “defective” children or intervening early to maximize disabled children’s development, the urgent drive to habilitate has persisted. During the first few years of a child’s life, this drive now meets neuroscientifically grounded exhortations to act *now*, in the “critical period,” before it is too late. The clock begins ticking even before birth: following her child’s microcephaly diagnosis nearing her third trimester of pregnancy, one mother I know was advised by a fetal medicine specialist to consume as many foods rich in Omega-3 as possible to improve her baby’s neurological outcome, which she dutifully did. Whether it is filling up on fatty acids or fidelity to therapeutic exercises and specialized pediatric nutrition at home, mothers invest major thought, time, and energy in

cultivating their children's bodyminds in hopes that their efforts will pay off in the future. And if, as Gavério and Lourenção (2020, 157) argue, rehabilitation therapeutics in Brazil today tend to "personalize each case in its specificities," it is mothers who become the "scientists" (Diniz 2017; Fleischer 2022) and experts in their individual disabled children's condition and needs, and whose hopes drive their pursuit of therapeutic technologies (Fleischer and Garcia 2022).

Potentializing the Children of Zika

One Thursday afternoon in 2016, at Abraço a Microcefalia's borrowed space in an old Catholic school in the Cidade Baixa (Lower City), while waiting for instructions from the volunteer coordinator to begin setting up for the weekly meeting with families, I snapped a photo of this "message of the month" with my cell phone:

Go for it! Risk it! There are times when you must believe in that silent voice inside you. The specialists don't always have the right answers. According to the laws of aerodynamics, bumblebees cannot fly. I think no one remembered to tell [the bumblebee] that!
KEEP FLYING!

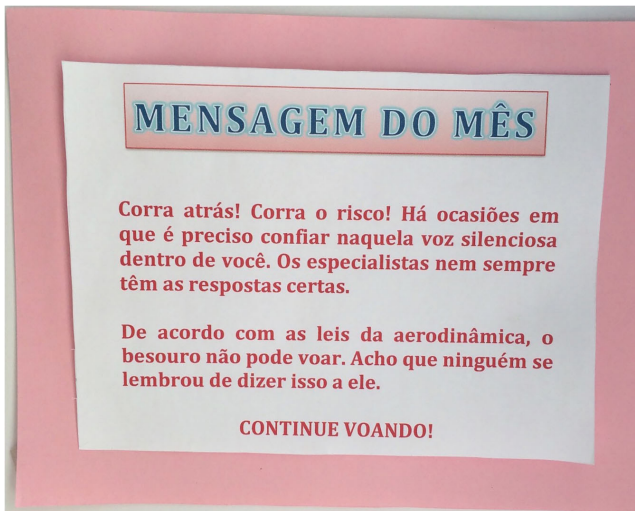


Figure 1. A sign hanging on the wall at the Abraço a Microcefalia headquarters in Salvador, Brazil, in 2016. Photo by K. Eliza Williamson.

The homemade motivational poster, confected by one of the volunteers using printer paper and light pink poster board, captures an important way parents viewed their young disabled children and their duty to continue investing in their habilitation, regardless of what “the specialists” might say. Because CZS is a new and rare condition, it remains in many ways an open case for clinical science. Doctors can make educated guesses, but it is still not known exactly to what extent children’s neurological malformations will impact their development as they grow, in what measure Zika’s damage to the central nervous system can be mitigated through therapeutic intervention, or even how long the children will live. For mothers, however, this uncertainty is both a source of anxiety *and* a reason for hope. If no one knows for sure what developmental heights their children may eventually be able to reach, then anything *might* be possible (Williamson 2018).

In working intensively with their children to take advantage of the early childhood period, mothers recruit diverse arrangements of therapeutic techniques and technologies into the everyday care of their disabled children, encouraging their developing bodyminds to reach their maximum potential. Habilitation cares for children’s *potential* abilities, laden with parental aspirations for the future, its landscape dotted with an ever-evolving constellation of technologies, techniques, and expertise. Maria, for example, scraped money together every month to pay for her son Bruno’s health plan. She also successfully sued the state for access to a specialized therapy program called Therasuit, described as “an intensive individualized therapy program that accelerates functional progress,” in which children in special canvas suits work with therapists while hooked up to various bungee cords in a “Spider Cage” to “learn new and correct patterns of movement through strengthening and functional skills practice” (Johns Hopkins Medicine n.d.). At R\$50,000 per year, this treatment would otherwise remain far out of reach for Bruno.

I interviewed Maria in 2017, shortly before Bruno turned two. Abandoned by the boy’s father early in pregnancy, she and her son relied mostly on Bruno’s government pension. She identifies as Black (*negra*) and, like Sara, lives in a periferia far from Salvador’s city center. Maria had completed part of a degree in social work and was employed by a shipping logistics company before becoming pregnant with Bruno, who was diagnosed with both CZS and cerebral palsy. On discharge from the hospital following his forty-day NICU (neonatal intensive care unit) stay, the neurosurgeon told Maria that her son’s brain was full of “water” (cerebrospinal fluid) and “almost [didn’t] have cephalic mass.” He picked up a roll of Micropore tape from his desk and held it up for her to see. The smaller, brown tube that held

the tape, he told her, should represent “water” (cerebrospinal fluid), and the much larger white tape itself should be the proportion of brain mass. “But his [Bruno’s] was the opposite: only this part here [the brown tube] is mass, and all of this [the tape] is water. . . . That means that he has almost no cephalic mass. That is, his development will be almost none. [And] if what he has is damaged by calcifications . . .” Maria trailed off. The neurosurgeon’s point was that her son’s prognosis was grim. “That right there left me a little upset [*um pouco afetada*],” Maria told me. Her facial expression when she told me this story gave away more than just “a little affected”; she clearly found the news devastating, and she later commented that she felt this a cruel way to have it delivered.

The day of our interview, Maria invited me along to Bruno’s scheduled therapy appointments, and we watched a team of therapists manipulate Bruno’s small body in succession. First is the physical therapist, who places Bruno on his belly and dangles a clinking toy about a foot in front of his head, with the idea that Bruno will practice lifting his head from the table and look toward the source of the sound. He does lift his head, with much effort, just for a moment. Maria’s face breaks into a proud grin as she points this out to the therapist. “That’s it, son!” she says.

Next, Bruno sees the speech therapist, who uses various techniques to stimulate the little boy’s oro-facial area. We sit on the floor in the darkened room, surrounded by objects of various sizes, colors, and textures. The therapist first massages Bruno’s jaw muscles to relax them, then uses a cotton swab to dab an edible paste just outside the corners of his mouth. This encourages him to lick the paste off with his tongue, working his lingual muscles and coordination—important for both eating and speaking. She shows Maria how to train her son’s verbal communication. With Bruno sitting on her lap facing us, she gently but firmly holds his chin between her thumb and forefinger, moving it down and back up as she slowly repeats “*ma-mãe*”—mommy—several times, exaggerating the pronunciation. This is to get Bruno to connect the feeling of the mouth movements with the vocalization of the word “mommy,” training him to verbally call Maria’s attention. Perhaps this constitutes more than simply a “functional” ability allowing him to call his primary caregiver’s attention when needed; it may also approximate the kind of reciprocity that parents expect from nondisabled children, and which many parents of cognitively disabled children long for: verbal recognition of his mother that approximates that of a nondisabled child (Rutherford 2020). Maria, the speech therapist emphasizes, is to repeat this exercise at home a few times a day. Maria nods understandingly; she already knows that frequently repeating the

exercises Bruno does in these short therapy sessions will maximize his developmental progress, and it is her responsibility to make sure this happens.

Habilitative care is not only, or even primarily, what happens in clinical settings, where doctors and therapists work with children and advise parents on their progress. Habilitative care also happens outside the clinic, in the home and other spaces in which children and their parents circulate—the homes of family members, clinics, hospitals, pharmacies, and grocery stores—and in precious leisure time at mall play-spaces, park playgrounds, and beaches. This is in good measure because, as clinicians stress to mothers especially, habilitative therapy is a daily activity that must be realized in the home as well as in the clinic. It requires what Cheryl Mattingly, Lone Grøn, and Lotte Meinert (2011) have called “chronic homework”: near-constant labor patients and their family members perform at home to manage chronic conditions. What can the chronic homework of habilitative care tell us about how parental aspirations for their disabled children become enfolded? I contend that it is in the micro-level practices of attending to small, developing bodyminds that parents not only imagine but *enact* futures for their disabled children, very often in hopes of defying what doctors predict.

Embodying Potential

In abstract terms, potentiality “is the always possibly realizable but never yet” that “comprises the ‘incorporeal materiality,’ the unseen capacities of other people and objects, that is always sensed by us, shaping the course of our actions” (Bryant and Knight 2019, 110). It is “the presence of an absence” (Agamben 1998, 179) that “gives us the future’s capacity to become future” (Bryant and Knight 2019, 115). But as Lynn Morgan (2013, 22; quoted in Bryant and Knight 2019, 126) reminds us, potentiality is also a *political* matter; it is “a discursive device that can be used to formulate, activate, or resist particular imagined futures.” Human actions can help someone or something realize potential—and inaction can leave this potential unrealized—and such choices have both ethical and political consequences. As Karen-Sue Taussig, Klaus Hoeyer, and Stefan Helmreich (2013, 6; my emphasis) note, “articulations of potential typically enact politics by working on and through morality, by making claims on us to *do something*.” To identify someone or something as having potential also foregrounds the necessity of making sure that potential is reached. Potential should not be squandered. But who has potential, and for what? Who determines this? What kinds of interventions are imagined to aid someone in reaching their full potential, and who has access to them?

While anthropologists have largely addressed potentiality in the context of high-tech biomedicine and the life sciences (e.g., [Gammeltoft 2013](#); [Rose 2007](#); [Taussig, Hoeyer, and Helmreich 2013](#); [Wanderer 2018](#)), imaginaries of potential also deeply imbue much more mundane or “prosaic” technologies of care ([Hart 2014](#)). High-tech or not, these technologies often involve a great deal of labor on the part of caregivers. Parents can become “case workers” coordinating care across a range of clinical specialties and geographical areas to maximize the benefits of treatment and therapy ([Sobo 2010](#), 222). This intensive labor is strongly bound up with gendered morality: mothers are the ones saddled with synchronizing this complex choreography, and cultural notions of motherhood can make habilitative care compulsory—“a ‘good’ mother will do the long-term care work” needed for maximum bodymind habilitation, and mothers have a “duty” to “capitalize on neuroplasticity,” thereby keeping up “a regimen of ‘neuronal fitness’” for their children” ([Mauldin 2016](#), 16; see also [Landsman 2009](#); [Pitts-Taylor 2016](#)). Mothers may gain a sense of hope from scientific discourses of neural plasticity, but the flip side is near-constant vigilance and endless care labor, since the plasticity of the brain is always “precarious,” vulnerable to regression as a result of not enough stimuli or exposure to the “wrong” stimuli ([Mauldin 2014](#), 145). Attending to habilitative care for disabled children’s potential allows us to ask new questions about plasticity, about how developing bodyminds are shaped, by whom, to what ends, and how this shaping is informed by, and in turn informs, ideas about what lives are considered worth living.

The various technologies mobilized around Lizinha’s and Bruno’s bodyminds—early-intervention therapy sessions, stimulating play techniques, a laborious ketogenic diet, imported CBD oil and nutritional supplements—are geared toward manipulating the disabled child’s bodymind to cultivate maximum developmental progress in the early years of life. Sara’s and Maria’s quest to provide their children with all they need to develop their sensory and motor skills to their maximum potential led these and other parents to invest much of their time and their family’s financial resources in their children’s habilitative care. The horizon of “results” is often murky, but these mothers imagined their children’s future abilities as actualizable through consistent, often self-sacrificial effort, as well as the right combination of substances and stimuli.

Disability studies scholar [Alison Kafer \(2013, 33\)](#) has asked, drawing on Jasbir Puar, “how are incidents of illness and disability inextricably bound, and differentially bound, to race/class/gender/nation?” The ability to project oneself into a future is not afforded to all children equally, since “some futures (and some bodies)

are more protected than others” (Kafer 2013, 34). We must therefore attend to the often “curtailed futures” (Kafer 2013, 42) of disabled and chronically ill people, especially the marginalized, for whom longevity is a privilege in a society that systematically wears them out and exposes them to death. This means attending to the social, cultural, and political conditions in which disability is lived; the contexts in which disabled children and their caregivers navigate the world matters (Rutherford 2020). Corporeal standards are culturally variable and unequally attainable for people with poor access to medical care, particularly those who are racially and economically marginalized like the families in my research. Many disability studies critiques of (re)habilitation, largely from the Global North, tend to assume the availability of all kinds of therapeutic options to everyone, everywhere, but this is not the case (Erevelles 2011). Bahian mothers’ investments in their children’s habilitation must be understood in the context of their projects of maternal care and the conditions of precarity in which they realize these projects. Through these investments, mothers assert that their children do indeed have potential, and that their bodyminds are worth habilitating, contesting narratives of their non-futurity that cast them as a “lost generation.”

Habilitating Potential, Cultivating Cure?

Undeniably, the impetus to habilitate, and the techniques and technologies mobilized in that habilitation, are embedded within social imaginaries of how children *should* be, what abilities they *should* have at the various stages of their development, and who is responsible for performing the therapeutic labor necessary to help them cultivate those abilities.

In our interview, Maria told me:

I strive [*luto*] for the cure, or for Bruno’s overcoming [*superação*] in many senses. And a lot of doctors don’t share our expectations. Dr. Anita [Bruno’s pediatric neurologist] . . . didn’t tell me that he wouldn’t be able to do anything; she said: “Stimulate him, and there will come a time when he will respond, because it will depend on the child. Because every case is its own case [*cada caso é um caso*]. There’s no way to say that he won’t do [things] because he has [cerebral] palsy.” But I know that there are many who think that he won’t be able to do one thing or another, [for example,] that he won’t walk. But for me, I work [with him] so that he can walk. I work with him so that he can talk. I do everything so that he can do things. (Maria, interviewed September 2017)

For Maria, the negative prognoses given by some health care professionals do not adequately consider her son's developmental potential. She prefers to listen to Dr. Anita, who insists on the hope of uncertainty ("There's no way to say that he won't . . .") and to follow Dr. Anita's advice to keep on stimulating him toward an unknown, aspirational goal of bodymind capacity that approaches that of a non-disabled child.

Scholars in critical disability studies have long critiqued rehabilitation as part of the "medical model" of disability, in which disability is framed as a problem that biomedicine can and should fix (e.g., [Albrecht 1992](#); [Barnes 2003](#)). [Colin Barnes \(2003, 4\)](#), for example, claims that the logics of rehabilitation turn "disabled people [into] objects to be cured, treated, trained and changed and made 'normal' according to a particular set of cultural values" (see also [Wendell 1996](#)). The historian [Henri-Jacques Stiker \(2019, 128\)](#) also asserts that rehabilitation is bent on standardization and assimilation into an imagined norm, "caus[ing] the disabled to disappear and with them all that is lacking, in order to assimilate them, drown them, dissolve them in the greater and single social hall." For these scholars, rehabilitation is designed to discipline disabled bodyminds to conform to a world that systematically excludes them, and is thus a materialization of *ableism*: "a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human [and in which] [d]isability . . . is cast as a diminished state of being human" ([Campbell 2009, 44](#)). Rehabilitative therapies manifest a *curative imaginary*, an imaginary "that not only expects and assumes intervention but also cannot imagine or comprehend anything other than intervention" ([Kafer 2013, 27](#); see also [McRuer 2006](#)). In *curative time*, "the only appropriate disabled mind/body is one cured or moving toward cure" ([Kafer 2013, 28](#)). And cure, [Kafer \(2013, 28\)](#) reminds us, encompasses not only the total eradication of bodymind impairment but also "normalizing treatments that work to assimilate the disabled mind/body as much as possible." The constraining logics of cure permeate disabled people's lives, constantly calling into question their value as persons and even their very existence. These logics have material consequences for disabled people, as they are subjected to all manner of therapies in the name of "fixing" their embodied differences. The logics of cure have material consequences, too, for those who care for disabled people, as they are recruited into projects of habilitation and rehabilitation, sometimes at the cost of their livelihoods and their own physical and mental health.

The habilitation of young children is wrapped up in a curative imaginary and unfolds in curative time. It is not just any bodymind that children are habilitated into, but one that approximates, as closely as possible, “the corporeal standard.” Habilitative therapies rely on ostensibly shared notions of what bodyminds should be able to do and at what point in the life course they should be able to do them. In wholeheartedly investing in their young disabled children’s future potential, are Bahian mothers participating in “an ethics of endless deferral” (Kafer 2013, 29) in which a nondisabled adulthood serves as an imaginary endpoint these children will never, because they cannot possibly, reach? The “potential” of child development on the whole undeniably bends toward a normative horizon. Parents grapple with the remaking of kinship and the life course, as Rayna Rapp and Faye Ginsburg (2011) point out, but they do so largely within the bounds of what is culturally appropriate to want for one’s children. Desired futures and the technologies they mobilize can be oppressive. Desired futures can also, however, constitute an important source of hope, particularly for marginalized people whose futures are systematically denied, and not just because of disability.

Kafer’s “political/relational model” of disability proves useful here. The political/relational model conceptualizes disability as a social and political rather than an individual “problem,” but it also does not oppose medical intervention outright, leaving room for desires for such intervention. Disabled people can both desire cure and identify politically with a wider disabled community (Kafer 2013, 6). So too, I argue, can parents of disabled children. The political/relational model thus maintains and expands the politicization of disability, permitting both critiques of ableism in all its forms *and* the space to imagine and bring about “a world which does not disable” (Crow 1996, 210; quoted in Kafer 2013, 8). By honoring desires for cure as well as the relationality of disability, this model allows us to understand parents of disabled children as something other than dupes of an ableist society bent on making their children “normal.” As Eli Clare (2017, 62) acknowledges, “Holding it all—sickness and human vulnerability, health and disability, the need for and the rejection of cure—is much harder work than writing anti-cure diatribes. And much more necessary.”

This appears especially important when considering the experiences of multiply marginalized people. Attending to habilitative care in Bahia draws our attention to how the intersections of race, class, and region further unsettle critiques of (re)habilitation originating in “white disability studies” based in the North Atlantic (Bell 2016). An “anti-cure” stance tends to obscure the structural and geopolitical violence that *produces* many disabilities, particularly in the Global South and among

marginalized communities in the Global North (Clare 2017; Erevelles 2011; Kafer 2013; Puar 2017). With Clare (2017, 56), I want to keep asking the thorny question, “How do we witness, name, and resist the injustices that reshape and damage all kinds of body-minds . . . while not equating disability with injustice?”

Maria holds tightly to her faith in Bruno’s potential, to the hope that his bodymind capacities might someday approximate those of children without his impairments. Her hope is active (Mattingly 2010), as she constantly works with him, “doing everything so that he can do things.” The therapeutic exercises in the clinic and at home, the constant search for the best treatments her limited money can buy—all of these are high-stakes endeavors that, with her steadfast perseverance, might lead to a less disabled future for her son. We must understand Maria’s talk of “overcoming” and “cure” in the context of her economic precarity and the “lost generation” narratives about children like Bruno that proclaim their utter lack of futurity. By investing in Bruno’s potential bodymind capacities through habilitative care practices, Maria actively contests these framings.

CONCLUSION

Mothers like Maria and Sara focus on their children’s potential, refusing medical and public narratives of limitations and impossibilities. They proudly speak of adversities already overcome, especially the ones that fly in the face of specialists’ authoritative knowledge. A large part of their time is spent amid the faltering of facts—the many moments when clinical science cannot tell them what to expect, or when new research contradicts what was previously believed, or when their children begin doing things doctors said they would likely never do. Continuing to invest in their children’s potential—materially, emotionally, and through care labor—marks a way of refusing prognoses they feel are unwarrantedly negative. Additionally, I contend, intensive investments in children’s developmental potential likewise constitute a way of refusing narratives that cast their children as lacking (worthwhile, livable) futures.

Certainly, we can sense a normative bodymind haunting Sara’s talk of “results” and Maria’s mentions of “striving for the cure” and “overcoming” congenital impairments. They aren’t working toward just any end goal, after all, but one in which their children’s embodied capacities come as close to those of a “typical” child as possible. But in cultivating these developing bodyminds through habilitative care, the two mothers also assert their children’s personhood as small people with lives worth living, children deserving of everything they need to reach their maximum potential. Children with a future. The stakes of making this assertion

are high when it comes to children labeled a “lost generation”: to ensure that their disabled children reach their full potential also means contesting narratives of failure and non-futurity. Habilitative caregiving thus makes claims about Bruno’s and Lizinha’s potential as people, as children deserving of therapeutic investment. Maria and Sara therefore work hard so that their children *might* someday develop skills like walking, feeding themselves, and speaking. The future remains uncertain, and this, too, is important here. In precarious lifeworlds, that tomorrow is not guaranteed lies at the forefront of mothers’ minds. With Brazil’s political and economic volatility, the means to access the health resources their children need, let alone pay for specialized treatments, hangs in the balance. Several of the mothers also worried that they may not be around long enough to see their children into adulthood (Williamson 2018). In a country with such stark socioeconomic and racial health disparities as Brazil, they might not be wrong.

Sara and Maria are under no illusion that their children will ever be “typical,” but they take it as their mission to get them as close as possible, doing everything they can to cultivate their potential. The moral and corporeal stakes are simply too high to do any less. So, perhaps rehabilitation is inextricably bound up with curative logics. But what to say about habilitation, where the temporal trappings of “re-” remain absent, and where—for small children with a novel congenital condition—the development of motor, sensory, and cognitive abilities seems open-ended? And more to the point, what are the stakes of habilitating these small bodyminds—or, indeed, of *not* habilitating them—particularly for families living in conditions of precarity in contemporary Brazil?

I have argued here that, in cultivating disabled children’s potential through habilitative caregiving, Brazilian mothers challenge pervasive narratives of non-futurity. Perhaps paradoxically, mothers like Maria and Sara refuse ableist assumptions about their children—for example, that the extent of their cognitive impairment makes them pitiable victims or renders their lives somehow less worthwhile or valuable—by fervently investing in the cultivation of their bodyminds toward a horizon of development that, while open-ended, is nevertheless traversed by normative ideals for being and acting in the world. But rather than automatically label habilitative care as ableist or not ableist, we should consider these intervention-laden forms of tending to developing children’s bodyminds as situated within particular lives. What is a “normative” life course in contemporary Brazil, particularly for precarious lives? What does a normative future look like for Black and Brown Brazilians who see people who look like them killed by state forces nearly every day on the evening news, and in their own neighborhoods (Smith 2016)?

Their aspirations to the good life are conditioned by these circumstances, as are the ways they find to manifest these aspirations through care for the developing bodyminds of their disabled children.

Sara and Maria, and all the mothers I've encountered in this research, know that the attitudes of others, even the structures of society, must change. They also know that they are the ones responsible for ensuring their children thrive within the yet unknown limits of their neurological condition. And they fiercely embrace this responsibility. Mothers thus carefully tend to their children's bodyminds in ways they understand will give these small humans the best possible chance at living in a world hostile to embodied difference.

As I finished writing this article, Bruno turned six. In a conversation with Maria over Zoom, she said, "I know my son will probably never be able to walk. But I continue to stimulate him, because the neurological system is a box of surprises, and you never know . . ." Even though the horizon of Bruno's bodymind potential has narrowed somewhat, Maria remains steadfastly hopeful, allowing the promises of neuroplasticity to light the way forward.

ABSTRACT

This article traces how Brazilian mothers raising children with congenital Zika syndrome cultivate their children's bodyminds through habilitative care—care that mobilizes a range of substances, technologies, and techniques to encourage maximum potential development of embodied abilities in young disabled children. Based on fieldwork conducted since 2016 with families impacted by the Zika epidemic in Bahia, Brazil, I argue that Bahian mothers' intensive investments in habilitative care constitute a way of asserting their children's deservingness of ongoing care and of contesting public narratives of their children's lack of futurity, thereby challenging exclusionary ideas about whose bodyminds are worth "potentializing." In dialogue with critical disability studies, I show how habilitative care is bound to discourses of "overcoming" and "curing" disability that scholars in this field have long criticized. I use my ethnography to unsettle these critiques, asking how to attend to the shaping of developing bodyminds amid the precarities of everyday life in the Global South. [disability; care; potential; rehabilitation; Zika; Brazil]

RESUMO

Este artigo examina como mães brasileiras com crianças diagnosticadas com a síndrome congênita do vírus Zika (SCVZ) cultivam os corpos-mentes dos seus filhos através de cuidado habilitativo—cuidado que mobiliza uma série de substâncias, tecnologias e técnicas para fomentar o desenvolvimento potencial máximo de habilidades corporificadas em crianças pequenas com deficiências. Baseado em pesquisa

de campo de natureza etnográfica, conduzida desde 2016 com famílias impactadas pela epidemia do vírus Zika na Bahia, Brasil, argumento que os investimentos intensivos das mães baianas constituem uma forma de reivindicar que os filhos merecem cuidado terapêutico e de contestar narrativas da sua falta de futuro, contestando, assim, narrativas repletas de ideias excludentes sobre quais corpos-mentes valem a pena “potencializar”. Dialogando com os Estudos Críticos de Deficiência, mostro como o cuidado habilitativo está ligado a discursos de “superar” e “curar” a deficiência, os quais este campo tem criticado há muito tempo. Lanço mão à minha etnografia para questionar estas críticas, perguntando como se pode pensar a moldagem de pequenos corpos-mentes em desenvolvimento no contexto das precariedades do Sul Global. [deficiência; cuidado; potencial; reabilitação; vírus Zika; Brasil]

NOTES

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1. All names here have been changed to protect interlocutors’ privacy. I have used the diminutive form of the pseudonym “Liza” here because both parents always referred to their daughter using the diminutive of her given name, a common practice in Brazil for loved ones.
2. Numbers here come from the latest available *Epidemiological Bulletin* issued by the federal government at the time of writing (vol. 54, no. 5, released April 3, 2023): <https://www.gov.br/saude/pt-br/centrais-de-conteudo/publicacoes/boletins/epidemiologicos/edicoes/2023/boletim-epidemiologico-volume-54-no-05/view>.
3. The full text of Constitutional Amendment 95 can be found here: http://www.planalto.gov.br/ccivil_03/constituicao/emendas/emc/emc95.htm.
4. Since 2019, when the Bolsonaro administration approved a *pensão vitalícia* (lifetime pension) for children with microcephaly, many families have switched from the BPC to this *pensão*. During fieldwork for this article, however, the BPC was the only option. The *pensão vitalícia* provides the same amount of money each month (one *salário mínimo*), but allows caregiving parents to work. Many of the mothers have since told me that little difference exists between the two, since the money does not suffice to pay for childcare to re-enter the job market anyway. The *pensão vitalícia* also stipulates that recipients cannot take the state to court, for example, for its negligence in allowing the spread of Zika and thereby failing to prevent the children’s malformations.

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