Gender, disability, and care: an ethnographic study of Congenital Zika Syndrome in Barranquilla, Colombia

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29th August 2024

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A thesis submitted for the degree of Doctor of Philosophy

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Language conventions

The data in this project was collected in Spanish. I have translated quotes and excerpts from fieldnotes and transcripts into English for inclusion in this thesis. Where there is not a translation available that fully captures the meaning of a term in Spanish, the original term is included. Terms in Spanish are italicised throughout, with the English translation in brackets following the first use of a given term.

I use 'disabled people' and 'disabled children' to refer to the way that people with certain bodily differences are disabled by structural barriers (Robertson, 2014). Some of the literature quoted uses the term 'children with disabilities', and in those instances the original wording is presented. Accepted language to describe disability differs between Spanish and English. Disabled child translates directly as *'niño discapacitado'* in Spanish, however, '*discapacitado(s)'* used on its own has a negative connotation – approximately equivalent to referring to someone as 'a disabled' or people as 'the disabled' – and is not widely used by disabled people or disability rights advocates. Participants most commonly referred to *'niños con discapacidades'*, in which case I use 'children with disabilities' in translated excerpts.

I use the term 'mother-carer' to refer to the women who participated in this research. As mothers and full-time caregivers for their children with CZS, they referred to themselves as '*madre-cuidadora'*. This term reflects the additional caregiving responsibilities that mothers of disabled children have.

Acronyms and abbreviations

COP: Colombian peso

CZS: Congenital Zika Syndrome

EPS: *Entidad Promotora de Salud* (health insurance agency)

HCP: Healthcare professional

INS: *Instituto Nacional de Salud* (National Institute of Health)

Minsalud: *Ministerio de Salud* (Ministry of Health and Social Protection)

SES: Socio-economic status/ strata

UCL: University College London

UN CRPD: UN Convention on the Rights of People with Disabilities

VEZ: *Vigilancia de Embarazadas con Zika* (Surveillance of Pregnancies with Zika)

Declaration

I, Rosamund Greiner, confirm that the work presented in this thesis is my own. Where information has been derived from other sources I confirm that this has been indicated in the thesis.

Research paper declaration form

I have included ideas in this thesis that I first developed in a published research paper. The details of that publication are below.

a) What is the title of the manuscript?
   Towards Critical Studies of Disabilities: engaging Latin American theoretical perspectives on Congenital Zika Syndrome
b) Please include a link to or doi for the work:
   https://doi.org/10.1590/S0104-71832022000300006.
c) Where was the work published?
   Horizontes Antropológicos
d) Who published the work?
   Programa de Pós-Graduação em Antropologia Social - IFCH-UFRGS
e) When was the work published? 2022
f) List the manuscript's authors in the order they appear on the publication:
   Rosamund Greiner
g) Was the work peer reviewed? Yes
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Abstract

The 2015 - 2018 Zika virus epidemic in the Americas resulted in the births of thousands of children with microcephaly, brain calcifications, and other damage to their nervous tissue. The cluster of symptoms associated with in-utero exposure to the virus has since been named Congenital Zika Syndrome (CZS). Many children born with the condition have significant additional care needs, and for most of them, their mothers provide the majority of this care. This thesis is an ethnography of families raising children with Congenital Zika Syndrome in Colombia, and the mothers in these families are the primary participants in the research. I adopt a critical perspective to explore the interlocking themes of gender, disability and care through an analysis of their experiences of caring for a child with CZS.

I explore the gendered division of labour that concentrates care work with the mother, and how this intersects with ableist discrimination against the child. I illuminate the barriers these women face as they try to access healthcare and education for their children, and their responses to these barriers. I discuss how mothers conceptualise their child's disability, and how they themselves experience discrimination and disablement, mediated by their caring role. Finally, I will examine how they experience time and think about their future with their child, in both individual and collective terms.

In this thesis, I draw on a range of disability theory, feminist perspectives, and decolonial thought, with a particular focus on Latin American Critical theory. I contribute a more complete theorisation of CZS as a disability. I also demonstrate how the intersection of gendered oppression and disability discrimination shape these mothers' experiences. I find that examining the interconnected experiences and embodiment of mothers and their children together is essential to arrive at a fuller understanding of the experience of raising children with CZS.

Impact statement

This interdisciplinary thesis has the potential to impact knowledge and practice in a range of academic and non-academic fields. The potential impacts of this research will be realised through the dissemination of findings to specialist audiences in relevant fields.

Within academia, the potential impact of this work is derived from the contribution to knowledge and development of theory in relation to a little known and poorly understood condition. This is an interdisciplinary piece of work that brings together perspectives from global health, medical anthropology and disability studies, and as such, has the potential to make an impact on research across these fields. This impact will be achieved through the dissemination of the findings in journal articles and conference papers. The findings of this research have been presented at anthropology and disability studies conferences, and interdisciplinary conferences focusing on Latin American studies and social studies of reproduction. One journal article has been published, and a further three original research articles will be prepared for publication in global health and medical anthropology journals based on this work.

The gendered responsibility placed upon mothers of disabled children has been explored extensively in the existing literature. In this thesis I have theorised that mothers experience the manifestation of structural ableism directed against their child, which precipitates a politicisation of the maternal role.

A considerable amount has been written on the barriers faced by children with CZS and other impairments and long-term conditions in accessing health and educational services in Colombia and Latin America more broadly. I have advanced this by exploring how caregivers respond to these barriers in order to gain access to care on behalf of their child. I have shown that in this case, caregivers sit at the centre of the health-care-treatment process, as they bring formal and informal healthcare spaces and resources into contact and reconstitute them in order to self-manage their child's health.

Disability as a category has been understood as a complex social phenomenon since the development of the social model of disability in the 1980s. I develop on these ideas, and prominent critiques of the social model, in two important ways. Firstly, I show that the social model is unable to fully explain how mother-carers conceptualise their child's disability. Secondly, I use theory of debility to show how impairment for both the mother and child are socially produced. Finally, I advance theories of crip time and disabled maternal lived time, showing how neo-liberal ableist policies and organisations impair maternal lived time.

Beyond academia, this research has the potential to impact policy and practice related to Congenital Zika Syndrome and family caregivers. This research has been disseminated to practitioners in order to inform their work. My access to the research participants was facilitated by the staff of the maternal and perinatal health research group at the National Institutes of Health in Colombia. This team have been conducting a cohort study with the participants since 2015, visiting Barranquilla to evaluate the children twice a year since enrolment. They have developed a strong rapport with the mothers and have anecdotal knowledge of the challenges that the families face. The doctors have made efforts to address these during past evaluation visits, for example by securing a sponsorship that provided incentives of free nappies and baby wipes to the participants. I presented an initial analysis of my data to the doctors, focusing on the barriers and challenges that the families face in accessing health care for their child, which substantiated much of what they had observed. One such example was a desire for increased access to psychosocial support for the mothers. They have used my results to inform their plans for future cohort study visits, with the intention of trying to address some of the broader social challenges that the families face.

Acknowledgements

I wish to thank the many individuals and organisations whose support has contributed to the successful completion of this thesis.

I am grateful for the funding I received from the UK Economic and Social Research Council through the UBEL Doctoral Training Partnership, and the additional fieldwork funding I received from the Chadwick Trust.

I wish to thank my primary supervisor Dr Jennie Gamlin for all of the guidance, support and encouragement she has offered me over the past five years. From the first (very) rough draft of my research proposal to the final thesis, her insight, knowledge and experience have been instrumental in the realisation of this piece of work. I am so grateful to my secondary supervisors, Professor Maria Kett and Professor Sahra Gibbon for their time, energy, enthusiasm and encouragement. I wish to thank Dr Jenevieve Mannell and Dr Dalia Iskander for their helpful feedback during my upgrade examination. I would like to thank Professor Maryam Shahmanesh and Dr Karen Lloyd for providing critical 'big picture' insights during my thesis committee meetings.

I am incredibly grateful to the members of the maternal and perinatal health team at the INS in Bogotá for adopting me as an honorary member of their brigade, sharing their expertise, and inviting me to present my results to them and their partners. I am indebted to Dr Marcela Daza in particular for her help in identifying participants and facilitating my involvement with the team.

In addition to those academics who have supported me in an official capacity, I am deeply thankful for the friendship and camaraderie of my colleagues in the Institute for Global Health. Every person who has checked in, asked "how's the writing going?", and offered a word of encouragement has helped motivate me to finish this project. I am especially grateful to Hattie Lowe, Faith Miller, Callie Daniels-Howell, and Alma Ionescu for the supportive and accountable reflexive discussions we have had over the years.

I am so grateful for the support of my friends and family. I want to thank my partner, Gareth, for all of the love, support, laughs, encouragement, commiseration and reality checks, and for reminding me that I can do anything I set my mind to. I am so thankful to my mum, Michelle, for always making time to listen to me, and offering her endless support for my pursuit of education. I couldn't have done it without you two, and I will be forever thankful.

Finally, my deepest thanks go to the women who participated in this research: Rita, Daniela, Patricia, Hilaria, Alba, Andrea, Julia, Catalina and Beatriz. From the bottom of my heart, I thank them for inviting me into their lives and for trusting me with their stories.

PART I: SETTING THE SCENE

Chapter 1: Background and context

The Zika virus shot to global attention in 2015 when a large-scale outbreak in Brazil lead to the discovery that the virus could cause congenital impairments, notably microcephaly, in babies whose mothers were infected during pregnancy. The cluster of symptoms associated with in-utero exposure to the virus has since been named Congenital Zika Syndrome (CZS). The scientific response to that outbreak and the emergence of CZS is chronicled in Debora Diniz's book 'Zika: from Brazilian Backlands to Global Threat' (2017). Ilana Löwy, in her book 'Viruses and Reproductive Injustice: Zika in Brazil' (2024a), finds that with the benefit of hindsight we see that this process actually happened in reverse; in 2015, Zika was constructed as a 'global threat', but when the threat did not materialise, the virus and its effects became neglected once more (Löwy, 2024b). The social impacts of CZS, continuing transmission of Zika, and affected countries outside of Brazil faded from the news and public consciousness, but the aftermath of the Zika epidemic continues to have a profound effect on children and their families. The aftermath of Zika in Barranquilla, Colombia is the subject of this thesis. This will be explored through the experiences of nine mothers raising children with CZS. Their pseudonyms for the purposes of this thesis are Rita, Daniela, Patricia, Hilaria, Alba, Andrea, Julia, Catalina and Beatriz. Since their children were born, they have dedicated themselves to caring for their children, learning about the condition, fighting for access to services, and striving to give their child dignity and a good quality of life.

Zika virus in the Americas

The Zika virus was first detected in Brazil in 2015 and by October of that year an association had been established between Zika infection and Guillain Barré syndrome in adults, and microcephaly, eye defects, preterm birth and low birth weight in babies born to women infected by Zika during pregnancy (Araujo, Ferreira and Nascimento, 2016; PAHO/ WHO, 2016; Hoen *et al.*, 2018; Ospina *et al.*, 2020). On 1st February 2016 the WHO declared the link between Zika and microcephaly and neurological disorders a Public Health Emergency of

International Concern (PAHO/ WHO, 2016). The virus is primarily spread by the bite of infected *Aedes* mosquitoes, and during 2016 cases of sexual transmission also began to be reported (Musso *et al.*, 2015; D'Ortenzio, Matheron and Yazdanpanah, 2016; Frank *et al.*, 2016; Venturi *et al.*, 2016).

The first case of Zika in Colombia was confirmed in October 2015, and over the following 6 months, over 65,000 cases of Zika virus were reported in the country, including almost 12,000 pregnant women (Pacheco *et al.*, 2016; PAHO/ WHO, 2016). By April 2016, four infants with confirmed congenital Zika infection had been born with microcephaly in the country, all to mothers who were asymptomatic when infected with Zika (Pacheco *et al.*, 2016). By January 2018, there had been 9,927 confirmed and 98,800 suspected Zika cases and 248 confirmed CZS cases in Colombia (PAHO, 2018).

Public health response

Prevention

The WHO initially recommended prevention and control interventions based on the Integrated Management Strategy for the Prevention and Control of Dengue, which consisted of vector management and personal protection (PAHO/ WHO, 2015). Vector management was carried out through eliminating *Aedes* mosquito breeding sites and using insecticides to remove adult mosquitoes (PAHO/ WHO, 2015). Recommended personal protection consisted of using bed nets (ideally treated with insecticides), wearing clothes that covered the limbs, using mosquito repellent and using screens on windows and doors (PAHO/ WHO, 2015).

The Colombian Ministry of Health and Social Protection (Minsalud) published comprehensive prevention and management plans, recommending bite prevention and vector removal, and laying out steps for monitoring pregnancies affected by Zika (2015, 2016a; Tolosa Pérez, 2016). Once the association with microcephaly was established, the WHO advised women who were pregnant or trying to get pregnant to avoid travel to affected areas (WHO, 2016a). Minsalud also issued advice that women should avoid or delay pregnancy until the Zika epidemic ended (2016b).

Monitoring and management of pregnancies

Minsalud (2016) recommended increased monitoring of all pregnancies where Zika was suspected, with such pregnancies treated as high risk and patients referred to an obstetrician or gynaecologist. They also required that blood samples from pregnant women with suspected Zika be sent to the municipal public health lab, and that all cases were reported to the Colombian Public Health Surveillance System (Minsalud, 2016b).

Colombia partially decriminalised abortion in 2006, allowing the procedure to be carried out legally if the pregnancy results from rape or incest, if the foetus has an abnormality incompatible with life, or when the life or health of the pregnant women is at risk (Corte Constitucional de Colombia, 2006)[1]. In 2016, in light of the growing Zika epidemic in Colombia, Minsalud (2016c) clarified that an abortion could legally be sought if a woman was infected with Zika during the pregnancy.

Clinical guidelines for patients with CZS

Clinical guidelines for the assessment, diagnosis and follow up of children with CZS in Colombia were published in 2016 (Minsalud, 2016d). The recommended therapeutic intervention for children with CZS consists of at least 30 minutes of one-to-one attention in physical, speech and occupational therapy per week with a focus on neuro-development (Minsalud, 2016d). The recommended health evaluation and monitoring consists of an evaluation by a neuro-paediatrician, geneticist, rehabilitation specialist, ophthalmologist, infectious disease specialist, and otolaryngologist (Minsalud, 2016d). Finally, it is recommended that that family should receive attention from a psychiatrist or psychologist and social worker (Minsalud, 2016d). The portion of these guidelines that relates to the follow up of symptomatic cases is shown in Figure 1.

[1] In February 2022, abortion was decriminalised in Colombia up to 24 weeks gestation (Corte Constitucional de Colombia, 2022).

Initial assessment:

- Evaluation by a neuro-paediatrician.
- Evaluation by a geneticist.
- Evaluation by a nutritionist.
- Evaluation by a physiatrist (physical medicine and rehabilitation specialist).
- Evaluation by an ophthalmologist.
- Evaluation by an infectious disease specialist.
- Evaluation by an otolaryngologist (ear, nose and throat specialist).
- Occupational, physical and language therapy (with attendance at least once per week, 30 minutes per session).
- Family intervention with psychiatry or psychology and social work.

Follow up assessments:

- Evaluation by a paediatrician at 2 and 3 months of age.
- Ophthalmology assessment before the age of 3 months.
- Hearing assessment before the age of 3 months.
- High-risk child growth monitoring consultation at 6, 9 and 12 months with an emphasis on neurodevelopment.
- Evaluation by a neuro-paediatrician at 3, 12 and 24 months.
- MRI at 24 months.
- Provide psychosocial support to the family, education to the mother, caregiver or family for the management of high-risk children.

Figure 1: Guidelines for the clinical follow up of children born with nervous system damage resulting from in-utero Zika infection. Adapted from (Minsalud, 2016d).

Academic response

The first months of the Zika virus epidemic were characterised by the rapid production of clinical research and development of interventions focused on vector control, surveillance, and development of treatments and vaccines (Waddell and

Greig, 2016; WHO, 2016b). Following this, the social causes and consequences of the Zika epidemic began to be explored.

The intersection between the Zika epidemic and sexual and reproductive health received considerable attention, and there was speculation that Zika may provide a window of opportunity to broaden access to abortion in the region (Roa, 2016; Killian, 2017; Carabali *et al.*, 2018; Wenham *et al.*, 2019). Zika has been analysed from the perspective of reproductive justice, highlighting the near impossibility of following the advice to avoid or delay pregnancy in the absence of comprehensive sex education, access to contraception and the availability of free, safe, legal and local abortion (Stern, 2016; Mohapatra, 2019; Stein *et al.*, 2022; Löwy, 2024a).

Structural inequalities and Zika

The Zika epidemic in Colombia was shaped by deep rooted structural inequalities (Wenham et al., 2019). The spread of the virus, ability to prevent infection and reproductive outcomes were all stratified according to overlapping gender, racial, and economic inequalities.

Living in poor quality housing without window screens or air conditioning, in densely populated neighbourhoods with poor sanitation, standing water, poor waste management and unreliable drinking water supplies increases an individual's risk of being bitten and infected with (Roa, 2016; Bond, 2017; Diniz and Andrezzo, 2017; Johnson, 2017; Diderichsen, Augusto and Perez, 2019). Insect repellent may also be beyond the budget of people living in low income households (Center for Reproductive Rights, 2018a). In Colombia, individuals of low socioeconomic status (SES) are placed on a subsidised utility bill tariff and enrolled in the subsidised social security system; both of these have been found to be associated with higher Zika prevalence at the municipal level (Kellemen, Ye and Moreno-Madriñan, 2021). Municipalities with higher population density and higher school dropout rates, both indicators of lower SES, also had higher Zika prevalence (Kellemen, Ye and Moreno-Madriñan, 2021). Interventions to improve sanitation and water supplies to communities were notably absent from the public health response to Zika (and other mosquito borne infections before it).

A number of researchers have identified gaps in prenatal care delivery in Zika affected countries during the epidemic. In regions of Colombia where the *Aedes* mosquito is endemic, only one third to half of women received the recommended number of prenatal visits (Castillo Ávila *et al.*, 2017; Ortiz-Grisolle *et al.*, 2019). Late initiation of prenatal care has been identified as a reason for not receiving an adequate number of prenatal check-ups (Ortiz-Grisolle *et al.*, 2019). Younger, single, less educated women on subsidised health insurance plans have lower odds of receiving at least four prenatal check-ups (Briceño-Ayala, Pinzón-Rondón and Zárate-Ardila, 2015; Castillo Ávila *et al.*, 2017). Inadequate quality of prenatal care had been observed prior to the start of the Zika epidemic, and "the Zika crisis revealed the weaknesses" in prenatal care services (Alvarado-Socarras *et al.*, 2023, p. 11).

The advice to avoid or delay pregnancy was difficult to follow in the absence of comprehensive sexual and reproductive health services and in a context of high rates of intimate partner violence (Davies and Bennett, 2016; Roa, 2016; Vélez and Diniz, 2016; Bond, 2017; Johnson, 2017; Worley and Bietsch, 2017; Mohapatra, 2019; Wenham *et al.*, 2019). Intersections between gender, SES, place of residence and education create a strong social gradient in reproductive health and autonomy.

In Colombia, rates of permanent sterilisation and modern contraceptive use are high and inequalities in contraceptive use by SES are low compared to other countries in Latin America (Leon *et al.*, 2019). However, the rate of unintended pregnancy and birth remains high (Guttmacher Institute, 2011). This may be explained by frequent change and discontinuation of contraceptive method (for reasons other than desire for pregnancy), resulting in periods of non-use that are not captured by point-in-time surveys that do not capture consistency or duration of contraceptive use (Bonneuil and Medina, 2009). The poorest and least educated women experience the greatest gap between wanted and actual number of children (Guttmacher Institute, 2011). Despite the changes to abortion law in 2006, a greater proportion of overall births in Colombia are unplanned (29%) than planned (27%) (Guttmacher Institute, 2011). This suggests that access to abortion remains an issue. Of the 44% of unintended pregnancies do end abortion, fewer than 1% are

reported as legal procedures (Guttmacher Institute, 2011). Unsafe abortion remains a major contributor to morbidity and is stratified by SES and place of residence (Guttmacher Institute, 2011).

IPV increases the risk of sexual transmission of Zika and of unplanned pregnancy directly through rape and indirectly through reduced contraceptive use (Pallitto and O'Campo, 2004; Maxwell *et al.*, 2015; Bond, 2017). One third of women in Colombia reported experiencing IPV in their current or most recent relationship (Bott *et al.*, 2019). IPV has been found to be a predictor of unintended pregnancy in Colombia (Pallitto and O'Campo, 2004). Poor women with limited access to resources may be more reliant on their partner and thus less able to leave situations of IPV (Bond, 2017).

While much of the evidence presented analyses SES, few studies explore the role of racial inequality. Despite the "myth of racial democracy" (Rodríguez Garavito et al., 2008, pp.8) Colombia, and Latin America more broadly, is marked by deep rooted racial inequality (Bratspies, 2020). Indigenous and Afro-Colombian people disproportionately experience poverty, have less education, are less likely to have health insurance, and are less likely to self-report being in good health compared to white or mestizo people (Bernal and Cárdenas, 2005; Rojas-Hayes, 2008; Freire *et al.*, 2018). 80% of Indigenous people and 55% of Afro-Colombian people belong to the lowest two wealth quintiles (Uribe *et al.*, 2015). Individuals existing at the intersection of race, gender and poverty are likely to experience a situation of unique marginalisation and vulnerability (ECLAC, 2016).

Disability in Colombia

Disability rights

The rights of disabled people are recognised within the Colombian constitution and protected by law. Colombia ratified the UN Convention on the Rights of People with Disabilities (CRPD) in 2011, which outlines the rights of disabled people to enjoy dignity, autonomy, independence, respect, full participation in society, freedom from discrimination, and equality of opportunities and access (UN General

Assembly, 2006). Since then, successive governments have enacted laws and reformed policies in order to bring them in line with the standard set by the CRPD (Correa-Montoya and Castro-Martínez, 2016). Law 1618, passed in 2013, "establishes the provisions to guarantee the full exercise of the rights of persons with disabilities", with a focus on social inclusion, removal of barriers, and the elimination of all forms of discrimination (Congreso de Colombia, 2013). Law 1438 of 2011 establishes that actors in the health sector must guarantee the right to health of persons with disabilities (Congreso de Colombia, 2011). Disabled people are entitled to a personalised rehabilitation plan, including the use of assistive devices, which should be developed by an interdisciplinary team with input from the individual (Toro-Hernández et al., 2019).

Disabled people in Colombia can obtain certification of their disability based on a clinical evaluation using the International Classification of Functioning, Disability and Health (ICF) guidelines (Minsalud, 2018). During this evaluation, the kinds of assistance and reasonable adjustments that the individual requires should be assessed by a clinician and included in the certification (Minsalud, 2022). This certification can be used to evidence claims for additional benefits and subsidies within the social protection system (Minsalud, 2020).

Per Colombian policy, disabled children enrolled in public schools should have a personalised plan outlining accommodations and supports that they required in order to participate and receive an inclusive education (Toro-Hernández et al., 2019). Additional funding should be provided to schools based on the number of enrolled disabled students, so that the schools can meet their students' needs (Toro-Hernández et al., 2019). Quotas and enhanced workplace protections have been introduced in order to promote disabled peoples participation in the workforce (Correa-Montoya and Castro-Martínez, 2016).

Social protection for disabled people

The social protection system in Colombia is divided into the *régimen contributivo* (contributory scheme) and *régimen subsidiado* (subsidised scheme) (Cabrera, 2011). Household socio-economic status is evaluated by the *Sistema Nacional de*

Identificación de Beneficiarios de Programas Sociales (National System of Identification of Beneficiaries of Social Programs, SISBEN), and each household is assigned a score between one and six, with one being the poorest (Cabrera, 2011). Households with scores between one and three are eligible for the subsidized social protection scheme (Cabrera, 2011). Members of the subsidised scheme are enrolled on a subsidised plan with an *entidad promotora de salud* (health insurance provider, EPS) and gain coverage for the basic package of medications, procedures and services included in the *plan obligatorio de salud* (mandatory health plan) (Bolivar-Vargas *et al.*, 2022).

Within the subsidised social protection scheme, families living in poverty or extreme poverty with children aged under 18 years old can also enrol in the *Familias en Acción* conditional cash transfer program and receive nutritional support and education grants (Cabrera, 2011). The nutrition component consists of a cash transfer for children up to six years old conditional on compliance with child health checkups, early childhood vaccinations and child health education sessions for mothers (DANE, 2011). The education component consists of a grant for each school-aged child in the household, conditional on school attendance (DANE, 2011). There are no additional subsidies available for disabled children.

Individuals enrolled in the subsidised scheme can access a subsidised pension for impoverished older people. A non-contributory pension for people over the age of 65 or living with moderate to severe impairment was proposed in 2007 but was not implemented (Pinilla-Roncancio, 2015). Formally employed and informal workers can enrol in the contributory pension scheme. The individual and their employer both contribute a percentage of the salary to the scheme (Cabrera, 2011). As with those in the subsidised scheme, they are enrolled with a health insurance provider through which they are covered for the same services included in the mandatory health plan (Cabrera, 2011; Bolivar-Vargas *et al.*, 2022). Members of the contributory scheme are also enrolled in a pension plan, occupational risk plan, and family compensation fund. Parents who care for an economically dependent disabled child (of any age) can access their pension early, provided they have made the

minimum amount of contributions (1,300 weeks or 25 years) (Ministerio de Justicia y del Derecho, 2022; Minsalud, 2024a).

Cajas de compensación (family compensation funds) are private, non-profit entities financed by social security contributions made by employers (Cabrera, 2011). They are intended to provide support for working families on low incomes (up to four times the minimum wage) who have children under the age of 18 or support older relatives (Ministerio de Justicia y del Derecho, 2018). They provide a cash benefit in the form of the *subsidio familiar* (family allowance) and also provide supplies such as clothing and text books, and discounted access to local recreation facilities (Ministerio de Justicia y del Derecho, 2018; Ministerio del Trabajo, 2023). Disabled children are eligible to receive double the usual family allowance payment (Minsalud, 2024b).

Gaps in social protection and the fulfilment of rights

Overall within the Colombian social protection system, "better-off formal workers have access to a full range of social protection benefits", while the social safety net is less comprehensive for those belonging to the lowest socio-economic strata (Garda and Arnold, 2022, p. 3). Disabled people and their caregivers face significant gaps in social protection. For example, some medical devices are included in the health benefits plan (part of the mandatory health plan), but others, including wheelchairs, are not covered (Minsalud, 2024c). Young families raising disabled children are unlikely to meet the requisite number of pension contributions to be able to access their pension before reaching retirement age, and no equivalent early pension provision is available for family caregivers in the subsidised scheme.

Disabled people in Colombia experience persistent barriers to accessing education, employment and health care services (Agudelo and Seijas, 2012). Disabled people face numerous barriers to accessing high quality health and rehabilitative services, including "therapeutic dispersion, difficulty in access to specialized care where necessary and prescribed by the attending physician, administrative and procedural barriers to access to services, and a lack of training in health care to meet with a focus on social inclusion and human rights" (Correa-Montoya and

Castro-Martínez, 2016, p. 79). Over half of people registered as having a disability do not attend any therapeutic services, with the most common reason for non-attendance being a lack of money (Correa-Montoya and Castro-Martínez, 2016). Access to health care services for disabled people has increased significantly since 2009 (Correa-Montoya and Castro-Martínez, 2016). However, disabled people living in major cities have far greater utilisation of health care facilities and services than those living in smaller cities and rural areas, which reflects differential barriers to access according to location (Correa-Montoya and Castro-Martínez, 2016). Furthermore, individuals with impairments who have not sought certification of their disability are not counted in these figures, and may face greater exclusion from services.

The implementation of policies related to assistive devices has been poor (Toro-Hernández et al., 2019). There are limited numbers of professionals who are trained on the provision and use of assistive devices, so it can be difficult to obtain an assessment and prescription (Toro-Hernández et al., 2019). Fragmented funding arrangements for those devices not covered in the mandatory health plan creates an administrative burden for individuals seeking access to assistive devices (Toro-Hernández et al., 2019). The provision of poor quality or inappropriate devices and lack of training for the disabled person and their caregivers on how to adapt to and use the device further limits their usefulness (Toro-Hernández et al., 2019). As a result, the potential of assistive devices to promote participation and inclusion has not been realised. Personal assistance is largely missing from Colombian disability policy, and together with the inadequate availability of assistive devices, this means that access to independent living is limited (Correa-Montoya and Castro-Martínez, 2016).

Just 14% of disabled people complete primary school and fewer than 1% complete secondary school (Agudelo and Seijas, 2012). 69% of disabled children (aged 7 – 14 years) have received no formal education at all, compared to 4% of non-disabled children in the same age group (DANE, 2023). The government has noted that the provision of inclusive education is hampered by a lack of appropriately trained staff and limited access to assistive technologies (Toro-Hernández et al., 2019). Given

their extremely limited access to education, it is unfortunate but unsurprising that disabled people are significantly less likely to be able to read and write at all age groups than non-disabled people in Colombia (DANE, 2023). Low educational enrolment and attainment, combined with workplace barriers and discrimination to contribute to low rates of employment for disabled people (Correa-Montoya and Castro-Martínez, 2016). Only 16% of working-age disabled people are in work, and of these, 98% earn below the minimum wage (Correa-Montoya and Castro-Martínez, 2016). The additional workplace protections in place may in fact work as a perverse incentive, dissuading employers from hiring disabled people (Correa-Montoya and Castro-Martínez, 2016). This persistent discrimination and lack of inclusion in education and work (re)produce economic disparities, with the result that 80% of disabled people belong to the bottom two socio-economic strata (Agudelo and Seijas, 2012).

Stratification of Congenital Zika Syndrome

Poor and marginalised women are at the greatest risk of contracting Zika, have the least control over their fertility, face significant barriers in accessing abortion and a high risk of complications if they do obtain one. Thus, children with CZS are more likely to be born into poor and marginalised families who have fewer resources available to overcome the systematic exclusion their children are at risk of facing. The unequal social structures of patriarchy and ableism underpin these challenges. With this in mind, I set out to determine how gender and disability are theorised in the qualitative literature concerned with people affected by Zika.

Literature review

Methodology of the literature review

I have set out to review the qualitative literature addressing people affected by Zika in Latin America. I am particularly interested in what the existing literature reveals about the gendered effects of the Zika epidemic and people's perceptions of disability. I am also interested in exploring how researchers theorise gender and disability in their work. Based on my familiarity with the academic literature on Zika

and CZS prior to conducting this review, I was aware that the application and development of theories of gender and disability within the quantitative literature on Zika and CZS was fairly limited. This, together with the need to narrow the scope of this review, influenced my decision to focus on qualitative and ethnographic literature. It is possible that important contributions developed in articles using primarily quantitative methods may have been omitted in this review, which is a limitation of the review.

In the years since the epidemic began, a number of qualitative studies of Zika have been published. Given the focus of this thesis on the application of theories of gender and disability to the case of CZS, I decided that a structured, critical, narrative synthesis of the qualitative literature with a focus on gender and disability would be appropriate.

Initial inclusion criteria were that articles should be primary, qualitative, peer reviewed articles whose participants consisted of populations directly affected by the Zika epidemic and CZS. Articles were screened for eligibility using the Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research (Joanna Briggs Institute, 2017).

In order to make this a truly critical review, I developed a set of critical review criteria that enabled me to evaluate the eligible literature (Gheondea-Eladi, 2015). I adapted Gheondea-Eladi's (2015) 'judgement criteria' based on my research question, choice of literature and the aims of my literature review. I then added and modified criteria while screening for eligibility and reviewing papers as common themes started to emerge to enable me to critically assess the entire corpus consistently in relation to these initial observations.

Results of the literature review

My systematic search resulted in the identification of 56, primary, qualitative, peer reviewed journal articles about the Zika virus epidemic in Latin America that included affected people (pregnant women infected with Zika and/ or caregivers of children with CZS) as their participants. 48 were conducted in Brazil and 8 in Colombia. Most studies described their overall approach only as qualitative, and

several described the research as exploratory or descriptive. Fifteen studies described their approach as ethnographic, two used photovoice, and two were mixed-methods studies with a quantitative component. The majority of studies used interviews to collect data, these were primarily semi-structured or in-depth/ narrative interviews. One study used an online form to collect free-text responses during the COVID-19 pandemic. Three studies used focus groups alone to collect data, and several others used these alongside photovoice or interviews.

Gendered experiences of Zika and CZS

A number of gendered impacts of the Zika virus epidemic, the public health response, and the aftermath of the condition have been highlighted in the extant literature.

The response to the Zika epidemic has been criticised for placing the responsibility for preventing pregnancy and avoiding Zika infection (thus preventing CZS) on individuals, especially on women of reproductive age (Coutinho *et al.*, 2017; Center for Reproductive Rights, 2018b, 2018c; Wenham *et al.*, 2019, 2021; de Melo *et al.*, 2020; Linde-Arias, Roura and Siqueira, 2020). This is borne out in the literature. The response of governments was found to place responsibility on individuals to avoid Zika rather than highlighting the responsibility of governments to provide public goods like sanitation, sexual and reproductive health services and mosquito control (Scott *et al.*, 2018; Albuquerque *et al.*, 2019; da Silva and Silva, 2020; de Melo *et al.*, 2020; Scott, 2020; Tirado *et al.*, 2020). This resulted in women being judged by other mothers, partners, relatives and healthcare professionals for getting pregnant while the risk from Zika remained, feeling that the full responsibility for the health of the pregnancy and the wellbeing of the unborn baby was placed on them, and feeling blamed for their child's condition (Carneiro and Fleischer, 2018; da Silva and Silva, 2020; de Melo *et al.*, 2020; Freitas *et al.*, 2020; Laza-Vásquez *et al.*, 2020; Tirado *et al.*, 2020; Vale, Alves and Carvalho, 2020; Moreira *et al.*, 2022; Alves *et al.*, 2023).

Obstetric violence was prevalent among women who were infected with Zika during pregnancy and those who were carrying a child affected by CZS (Carneiro and Fleischer, 2018; Mocelin *et al.*, 2021). Women's reproductive auton.omy was taken

away (e.g. pursuit of a termination) by health care professionals (HCP) withholding information about the health of the pregnancy and diagnosis of CZS (Mocelin *et al.*, 2021). Some women wanted information about the possibility of terminating the pregnancy, but this was not forthcoming from HCP (Marbán-Castro et al., 2022). For those who did have the opportunity to talk about termination, this was handled poorly. Mothers had personal objections to abortion but they felt pressured by healthcare professionals to terminate their pregnancies and judged when they refused (Marbán-Castro et al., 2022). HCP disparaged the women, referring to them using terms like "little woman" that reified the power imbalance between them (Mocelin *et al.*, 2021). HCP also ignored women or treated them poorly during the birth (Mocelin *et al.*, 2021).

The expectation that individual women will take full responsibility for the Zika epidemic does not stop with pregnancy and infection. In the majority of cases, mothers are the primary caregivers for children with CZS (de Sá *et al.*, 2017; Carneiro and Fleischer, 2018; Albuquerque *et al.*, 2019; Smythe *et al.*, 2019; da Silva and Silva, 2020; de Melo *et al.*, 2020; Freitas *et al.*, 2020; Junqueira *et al.*, 2020, 2022, 2022; Mendes *et al.*, 2020; Scott, 2020; Tirado *et al.*, 2020; De Sá and Pletsch, 2021; Costa *et al.*, 2022; Laza-Vásquez, Briones-Vozmediano and Gea-Sánchez, 2022; Moreira *et al.*, 2022; Alves *et al.*, 2023). Fathers tended to maintain 'traditional' roles, providing for the family through waged work, while the mothers did the majority of the care work (Félix and de Farias, 2018; Scott *et al.*, 2018; Smythe *et al.*, 2019; de Melo *et al.*, 2020; Junqueira *et al.*, 2020). Mothers identified a need for this to change and for fathers to become more involved in childcare, whereas fathers did not raise this as an issue (Smythe *et al.*, 2019). With the arrival of the COVID-19 pandemic, fathers took responsibility for chores that required someone to leave the house, while mothers tended to stay at home with the child (Vale *et al.*, 2021).

Relationships between parents sometimes changed with the arrival of a child with CZS, and some fathers left their families (Scott *et al.*, 2018; Freitas *et al.*, 2020; Tirado *et al.*, 2020; Vale, Alves and Carvalho, 2020). They felt that in caring for a child with CZS, women became mothers first rather than wives, and they also predicted an increase in the amount of domestic work they would be expected to complete,

which they were unwilling to do (Scott *et al.*, 2018). Fathers disapproved of mothers spending so much time out of the home, as this went against the norm, but were reluctant to take the child to appointments themselves (Fleischer and Garcia, 2022). In some cases, fathers took on an auxiliary caring role and 'helped' with roles traditionally assigned to mothers (Scott *et al.*, 2018; de Melo *et al.*, 2020; Junqueira *et al.*, 2020, 2022; Scott, 2020; Azevedo, Freire and Moura, 2021). In other cases, they took on an emotional role in the family, providing emotional support to the mother (Félix and de Farias, 2018). A minority of couples reported that they grew closer and felt a sense of unity as they learned together about CZS and how to care for the child (Morris *et al.*, 2022). Within those couples that stayed together, there was a tendency among some mothers to construct involved fathers as heroic "super dads" (Moreira *et al.*, 2022). Implicit in this was a belief that an engaged father who showed affection for a child with CZS was considered more special and rare than a loving and engaged mother (Moreira *et al.*, 2022).

Support from other relatives with childcare was mixed. Some mothers could rely on support from relatives, and this helped them cope (Campos *et al.*, 2020; de Melo *et al.*, 2020; Junqueira *et al.*, 2020; Lima *et al.*, 2020; Romero-Acosta *et al.*, 2020). Others lacked family support with childcare (Duarte *et al.*, 2019; da Silva and Silva, 2020; Freitas *et al.*, 2020; Mendes *et al.*, 2020; Romero-Acosta *et al.*, 2020). In some cases mothers believed that other relatives (including fathers) were incapable of meeting the child's needs (Williamson, 2018; Duarte *et al.*, 2019; Freitas *et al.*, 2020; Scott, 2020; Laza-Vásquez, Briones-Vozmediano and Gea-Sánchez, 2022). Indeed this was borne out in the story of one mother who left her son with his father while she ran errands and received repeated calls from him with questions about how he was supposed to care for the boy (Williamson, Engel and Fietz, 2023). Even when relatives did play a role in childcare, mothers did not receive sustained and consistent support (Junqueira *et al.*, 2020) and some mothers felt that the family treated the child with CZS differently to other children in the family (Scott, 2020). Where family members did offer support, this was mainly grandmothers, sisters and daughters (Scott *et al.*, 2018; de Melo *et al.*, 2020; Mendes *et al.*, 2020; Romero-Acosta *et al.*, 2020; Scott, 2020). In some cases, the mother delegated the care of her other children to a relative so that she could focus her energy on the child with CZS

as their needs were more complex (Junqueira *et al.*, 2022). Indeed, female relatives were seen as the natural choice to assist mothers even when they did not wish to become involved (Scott *et al.*, 2018; Scott, 2020). Fathers who 'helped' with care responsibilities received praise, whereas mothers and female relatives completing the same tasks routinely did not, demonstrating the gendered expectations for care work and the undervaluation of women's labour (Scott *et al.*, 2018; Moreira *et al.*, 2022).

Some mothers were able to help their partners and other family members learn how to care for the child with CZS (Smythe *et al.*, 2020; Vale, Alves and Carvalho, 2020; Dias *et al.*, 2021), and specific interventions for parents of children with CZS helped improve the mothers' confidence to share their skills (Smythe *et al.*, 2020; Dias *et al.*, 2021). When they took steps to facilitate the involvement of fathers, such interventions also benefitted fathers (Smythe *et al.*, 2019). These interventions also enabled fathers to gain skills, giving them confidence to be competent and engaged caregivers (Smythe *et al.*, 2019). Barriers to men's involvement in these interventions were also identified. Women tend to be the ones invited to services and interventions, and they become the gatekeeper for the fathers' attendance (Smythe *et al.*, 2019). Mothers wanted fathers to become more involved and capable of providing childcare, but also valued having female-only spaces to seek support, so they sometimes end up having to make a choice between these conflicting priorities (Smythe *et al.*, 2019). Interventions also need to fit around work hours to maximise the fathers' ability to engage, since as noted they tend to remain in employment after the arrival of the child with CZS (Smythe *et al.*, 2019). Interventions need to respond to fathers' needs and wishes in order to engage them, which include showing fathers in pictures, and giving practical, skills based resources and sessions (Smythe *et al.*, 2019).

The lack of childcare support combined with the intensive routine of appointments and stimulation activities resulted in mothers spending lots of time and energy caring for the child with CZS (de Sá *et al.*, 2017; Williamson, 2018; Albuquerque *et al.*, 2019; da Silva and Silva, 2020; de Melo *et al.*, 2020; Freitas *et al.*, 2020; Junqueira *et al.*, 2020, 2022; Mendes *et al.*, 2020; Scott, 2020; Vale, Alves and Carvalho, 2020; De

Sá and Pletsch, 2021; Laza-Vásquez, Briones-Vozmediano and Gea-Sánchez, 2022; Vale, Cândida Cordeiro and Souza de Santana Carvalho, 2022; Williamson, Engel and Fietz, 2023). While fulfilling these activities, along with caring for any other children in the family and completing regular household chores, it was difficult for mothers to find time to care for themselves, rest or engage in leisure activities (de Sá *et al.*, 2017; Williamson, 2018; Duarte *et al.*, 2019; Calazans *et al.*, 2020; Freitas *et al.*, 2020; Mendes *et al.*, 2020; Scott, 2020; Vale, Alves and Carvalho, 2020; Junqueira *et al.*, 2022; Laza-Vásquez, Briones-Vozmediano and Gea-Sánchez, 2022; Morris *et al.*, 2022; Williamson, Engel and Fietz, 2023). In some cases mothers had to choose between their own health and that of their child, exemplified by one mother who avoided having necessary surgeries as the recovery would prevent them caring for their child, and another who skipped appointments for the child so that she had time to rest (Williamson, 2018; Junqueira *et al.*, 2020). In some cases, mothers self-medicated when they were unwell as they were unable to find someone to care for the child while they went to the doctor (Williamson, Engel and Fietz, 2023). This created a conflict for mothers, who recognised that they needed to maintain their own health in order to continue caring for the child, but lacked the support to do so (Laza-Vásquez, Briones-Vozmediano and Gea-Sánchez, 2022)

Initially, having a child with CZS made it harder for women to accept the transition to motherhood (da Silva and Silva, 2020; de Melo *et al.*, 2020). However, motherhood eventually became an all-consuming identity, taking prominence above all other aspects of their identities (de Sá *et al.*, 2017; Pinheiro, 2018; da Silva and Silva, 2020; de Melo *et al.*, 2020; Freitas *et al.*, 2020; Mendes *et al.*, 2020; Scott, 2020). Mothers shared that they had to 'give up on their dreams' (De Sá and Pletsch, 2021) and no longer feelt like women but instead became defined by their role as the primary caregiver for a child with CZS (da Silva and Silva, 2020; de Melo *et al.*, 2020). Being a 'Zika mom' or a mother to a 'Zika child' became a social identity (Vale, Alves and Carvalho, 2020). The "mother-child dyad" also became a powerful symbol and leveraging these identities became essential in negotiating access to care and services for the child with CZS (Scott, 2020, p. 6).

Mothers formed networks and communities around the social identity of the 'Zika mom', particularly in Brazil, where cases were more geographically concentrated. Meeting other parents of children with CZS showed them that they were not alone, and they appreciated the opportunity to speak about challenges and suggestions, express emotion and be listened to (Smythe *et al.*, 2019). Within these networks they shared information and experiences, donated and swapped items, share medicines and orthoses (Valim, Marques and Lustosa, 2021). There networks emerged in response to the "insufficiency of public policies or the lack of resources to meet the demands and needs of children and caregivers" (Valim, Marques and Lustosa, 2021). Over time these spaces of peer support became sites of political self-organisation, and mothers formed associations to engage in collective action on behalf of their children (Pinheiro, 2018; Azevedo, Freire and Moura, 2021; Fleischer and Garcia, 2022). Being a 'Zika mom' became a political identity to organise around and a source of solidarity through the process of working together to increase the visibility of their struggles, mobilise others, highlight prejudice and discrimination, fight for rights, demand access, and work to build capacity within their organisations (Pinheiro, 2018; de Melo *et al.*, 2020; Mendes *et al.*, 2020; Scott, 2020; Simas *et al.*, 2020; De Sá and Pletsch, 2021). In Colombia, there is less evidence of mothers political organisation around the social identity of the 'Zika mom'.

In many cases, mothers stopped working in order to dedicate themselves to the care of their child with CZS (Scott *et al.*, 2018; Albuquerque *et al.*, 2019; da Silva and Silva, 2020; de Melo *et al.*, 2020; Freitas *et al.*, 2020; Mendes *et al.*, 2020; Scott, 2020; De Sá and Pletsch, 2021). If one parent needed to leave work to care for the child, the expectation from fathers was that this would be the mother (Félix and de Farias, 2018). Employers pushed women out even when they wanted to continue working, because they believed that the increased care needs of a child with CZS would make their mothers unreliable employees (Freitas *et al.*, 2020). Mothers who initially continued working found that day-care services were not equipped to care for children with CZS, forcing them to quit (Williamson, 2018).

Theoretical perspectives on gender

Within the qualitative literature on Zika and CZS, a number of authors have drawn on theories of gender in their analysis. Several authors have adopted an intersectional approach, drawing attention to the particular challenges that are produced by the intersection of low SES, racialisation and gender inequality for mother-carers of children with CZS (Félix and de Farias, 2018; Williamson, 2018, 2020, 2024; da Silva and Silva, 2020; Valim, Marques and Lustosa, 2021). In particular, reproductive autonomy, the gendered division of labour, and social construction of motherhood have been addressed by authors.

A number of studies have investigated reproductive decision making in light of the Zika epidemic, and a smaller number have examined restrictions on reproductive autonomy as a cause and consequence of gender inequality (Carneiro and Fleischer, 2018). Conservative gender norms limit access to sexual and reproductive health services, restricting women's ability to control their own fertility (Tirado *et al.*, 2020). One study identified a preference for tubal ligation after the birth of the child with CZS (Carneiro and Fleischer, 2018). The authors propose that this represents women's desire to take control of their fertility in a context of patriarchal norms of reproduction around "the use of a condom, machismo in conjugal relations, and the overload of the woman as the only one responsible for reproduction" (Carneiro and Fleischer, 2018, p. 716). They also highlight that women's lack of reproductive autonomy on the basis of gender is compounded by low SES (Carneiro and Fleischer, 2018).

Several authors point to the gendered division of care work as both indicative of and perpetuating gender inequality (P. S. Oliveira *et al.*, 2019; Freitas *et al.*, 2020; Vale, Alves and Carvalho, 2020). They draw links between the gendered division of labour, the devaluation of care work through its feminisation and naturalisation to women and the gendered cycles of care work and poverty (Albuquerque *et al.*, 2019; de Melo *et al.*, 2020). As Albuquerque and colleagues put it, "it is the mothers who are the main caregivers, who spend time and energy on the direct care of their children, who lose their jobs, reinforcing the process of the feminization of care and its relationship with female impoverishment" (2019, p. 505).

A number of authors show that public policy responses to Zika did not take account of existing gender inequality (Freitas *et al.*, 2020). Not only did they take the gendered division of labour for granted, but reinforced and deepened it (Albuquerque *et al.*, 2019; de Melo *et al.*, 2020). De Melo and colleagues point out that "public policies were formulated without taking account of the time required for the care, and this resulted in the state appropriating the women's time and reinforcing gender roles that maintain women, almost exclusively, as mothers and carers" (2020, p. 13). Smythe and colleagues (2019), recognising that the arrival of a child with high support needs can deepen the gendered division of labour, designed an intervention aimed to address this by involving fathers in a parenting intervention.

The gendered division of labour is highly entangled with the social construction of motherhood, and what makes a 'good' or 'bad' mother shifts in the context of disability. 'Good' motherhood is contingent on producing a 'perfect' child, so the very existence of a child with CZS reduces the mother's proximity to the maternal ideal (Vale, Alves and Carvalho, 2020). The maternal ideal excludes mothers raising children with disabilities, and trying to adhere to such a standard becomes even more exhausting and demoralising for mothers (Vale, Alves and Carvalho, 2020). Disability discrimination and a lack of accessible public services creates poor health outcomes among children with CZS, but the blame for this is directed at mothers, reflecting patriarchal norms of parenthood under neoliberalism (Carneiro and Fleischer, 2018; Freitas *et al.*, 2020).

Scott and colleagues (2018; 2020) bring together the social construction of motherhood with the gendered division of labour, offering a more in-depth analysis from a feminist perspective. They point out that under a gender system that associates attributes such as "dedication, selflessness and sacrifice" with 'good' womanhood, women can attain some level of social capital through demonstrating their dedication to care work as mothers (Scott *et al.*, 2018; Scott, 2020, p. 1). In the case of CZS, where caregiving routines are intensified and state support services are fragmented, the amount of dedication and selflessness demanded by the maternal role is amplified. Scott (2020) shows how they can leverage social

expectations of motherhood to negotiate access to care on behalf of their child, though he highlights that this concentrates care with the mother, reinforcing the gendered division of labour.

The qualitative literature on gendered care work in the context of CZS (as with disability more broadly) demonstrates that the gendered division of labour overburdens women and can have negative consequences for their mental health (da Silva and Silva, 2020). Through deep ethnographic engagement with mother-carers in Brazil, Williamson has further elucidated the consequences of such intensive routines of care within the domestic sphere. She shows that the gendered division of labour is deepened in the case of disability as mother-carers are left with no choice but to leave their jobs to care for their child full time (Williamson, 2023). This full-time caring role involves engaging their children in therapeutic exercises, researching medical and therapeutic interventions including dietary supplements, and in some cases bringing legal cases to demand better care and support (Williamson, 2023). The time investment, lack of help, and financial strain involved in keeping up with this exhaustive care routine are physical and mentally debilitating to mother-carers (Williamson, 2023; Williamson, Engel and Fietz, 2023).

Experiences of ableism

It is evident in the existing literature that societal ableism has shaped the lives of children born with CZS, and has had a profound impact on their primary caregivers as well.

The vicious cycle of disability and poverty is apparent at the household level in the literature on Congenital Zika Syndrome. In many cases, mothers gave up working to care for the child with CZS and were unable to return to employment as they could not afford to pay for childcare (Williamson, 2018; Albuquerque *et al.*, 2019; Duarte *et al.*, 2019; de Melo *et al.*, 2020; Freitas *et al.*, 2020; Mendes *et al.*, 2020; Ambrogi, Brito and Diniz, 2021; Azevedo, Freire and Moura, 2021; De Sá and Pletsch, 2021; Junqueira *et al.*, 2022; Morris *et al.*, 2022; Williamson, Engel and Fietz, 2023). Other mothers gave up studying to care for the child, not only putting their education on hold but limiting their future earning potential (Freitas *et al.*, 2020; Junqueira *et al.*,

2022; Williamson, Engel and Fietz, 2023). Some mothers did re-enter the workforce once their child was older (Azevedo, Freire and Moura, 2021; Fleischer and Garcia, 2022; Laza-Vásquez, Briones-Vozmediano and Gea-Sánchez, 2022). Deciding whether or not to return to work was a difficult decision, especially for those mothers who had the greatest level of financial need and were concerned that they would lose access to benefits and subsidies for their child if they went back to work (Ambrogi, Brito and Diniz, 2021). In a few cases, support from fathers enabled mothers to stay in employment after the arrival of the child with CZS (Lima *et al.*, 2020). In some cases, mothers gave up the child with CZS for adoption, citing a lack of financial resources to care for them (Pinheiro, 2018).

Women spent a considerable amount of time trying to gain access to benefits and subsidies to help them meet the child's needs (Pinheiro, 2018; de Melo *et al.*, 2020; Scott, 2020). Benefits were tightly capped according to strict criteria defining financial need, which made them difficult to access (Scott *et al.*, 2018; Albuquerque *et al.*, 2019; Duarte *et al.*, 2019; Vale, Cândida Cordeiro and Souza de Santana Carvalho, 2022). Some families were in dire financial need but were not getting benefits (Ambrogi, Brito and Diniz, 2021). This was mostly due to the administrative burden involved in applying and proving financial need, or because they had been incorrectly informed by staff that they couldn't claim more than one benefit at the same time (Ambrogi, Brito and Diniz, 2021). Some healthcare professionals also expressed a belief that caregivers were working the system to get more than they were owed (Simas *et al.*, 2020). In reality, for many families, the benefits they were able to claim did not provide enough money to cover the additional costs associated with caring for the child (Scott *et al.*, 2018; Albuquerque *et al.*, 2019; Scott, 2020; Junqueira *et al.*, 2022; Morris *et al.*, 2022; Vale, Cândida Cordeiro and Souza de Santana Carvalho, 2022). For those who had given up work, the benefits they were entitled to did not make up for loss of earnings (Morris *et al.*, 2022).

As a result of the limited state support and additional out of pocket costs of caring for a child with CZS, caregivers experienced financial strain (Pinheiro, 2018; Scott *et al.*, 2018; Duarte *et al.*, 2019; Freitas *et al.*, 2020; Laza-Vásquez, Briones-Vozmediano and Gea-Sánchez, 2022; Vale, Cândida Cordeiro and Souza de Santana Carvalho,

2022). Mothers expressed that they wanted more financial support to help them meet their child's care needs (Marbán-Castro *et al.*, 2022). Fathers reported experiencing financial strain as they tried to cover the additional out of pocket costs (Félix and de Farias, 2018). Families reported that they couldn't afford to replace orthoses and wheelchairs that the children outgrew (de Lima Nascimento Coutinho *et al.*, 2023). Transport to therapy and health appointments was unaffordable (Mendes *et al.*, 2020). I will discuss the impact of these financial difficulties on the child's health and development in the next section.

The COVID-19 pandemic exacerbated these issues. Families reported that the economic impact of COVID-19 mimicked that of Zika, as job losses decreased their household income (Valim, Marques and Lustosa, 2021). Mothers highlighted that the challenges of COVID-19 came amid wider cuts to public services in Brazil under President Bolsonaro (Valim, Marques and Lustosa, 2021). Prior to the pandemic, children received donated supplies like nappies through their attendance at in-person services (Valim, Marques and Lustosa, 2021). They tried to address the shortfall in funds and donations during COVID-19 by crowdfunding (Valim, Marques and Lustosa, 2021).

Barriers to health and therapeutic services

Mothers encountered challenges in getting access to suitable health and therapeutic services for the child with CZS (da Silva and Silva, 2020; de Melo *et al.*, 2020; Mendes *et al.*, 2020; Tirado *et al.*, 2020; Mocelin *et al.*, 2021). They identified a lack of specialised professionals available to provide care for their child (Scott *et al.*, 2018; Campos *et al.*, 2020; Vale, Cândida Cordeiro and Souza de Santana Carvalho, 2022). They reported that specialised healthcare professionals would not do home visits (Duarte *et al.*, 2019). They found that the therapy services available to their child were poor quality (Albuquerque *et al.*, 2019), with broken equipment and lack of materials at therapy centres (Scott *et al.*, 2018), short appointments, and limited one to one attention from staff (B. S. B. Oliveira *et al.*, 2019; Fleischer and Garcia, 2022). High quality therapies were oversubscribed, so mothers would settle for lower quality services as a temporary measure while they were on the waiting list for a better service (Fleischer and Garcia, 2022). Mothers identified alternative types of

therapy that they believed would benefit their child's development (such as hydrotherapy) but found that they were not available (Vale, Cândida Cordeiro and Souza de Santana Carvalho, 2022).

In some cases, mothers who were struggling to gain access to services through official referral pathways secured access to services through personal connections and informal channels (Albuquerque *et al.*, 2019). This can reinforce existing inequalities as services are provided on the basis of social capital and professional connections rather than according to the child's health and development needs. Children belonging to families of greater economic means received more specialist care, as their caregivers found it easier to arrange transportation to appointments (de Melo *et al.*, 2020). Mothers who had greater financial resources considered seeking private health provision to complement public offering (Scott, 2020).

Mothers reported that health and therapeutic services were located far away from their homes, fragmented, and concentrated in state capitals and larger cities (Scott *et al.*, 2018; Albuquerque *et al.*, 2019; B. S. B. Oliveira *et al.*, 2019; Junqueira *et al.*, 2020; Mendes *et al.*, 2020; Scott, 2020; Morris *et al.*, 2022; Vale, Cândida Cordeiro and Souza de Santana Carvalho, 2022). The location of services created significant barriers to access. Mothers had difficulty getting to appointments due to lack of suitable transport (Félix and de Farias, 2018; Campos *et al.*, 2020; de Melo *et al.*, 2020; Freitas *et al.*, 2020; De Sá and Pletsch, 2021; Vale, Cândida Cordeiro and Souza de Santana Carvalho, 2022). In some cases, public transport did not serve the main therapy centres (Ambrogi, Brito and Diniz, 2021). Where public transport options were available, they were often inaccessible to them when traveling with their child (Mendes *et al.*, 2020; Scott, 2020; Fleischer and Garcia, 2022). Mothers sometimes had to catch multiple buses to reach a therapy centre, so the journeys were long and slow (Morris *et al.*, 2022). Mothers found these journeys time consuming and expensive (Albuquerque *et al.*, 2019; Campos *et al.*, 2020; da Silva and Silva, 2020; Freitas *et al.*, 2020; Scott, 2020; Ambrogi, Brito and Diniz, 2021; Vale, Cândida Cordeiro and Souza de Santana Carvalho, 2022). In particular, they expressed their frustration at the need to undertake long, difficult journeys to attend short, poor quality therapy appointments (Fleischer and Garcia, 2022).

Some families were provided with more accessible transport, or lived within cities that had large therapeutic centres. Transportation services provided by municipal authorities was often cramped and unreliable, and the journey times were still excessive (Fleischer and Garcia, 2022; Vale, Cândida Cordeiro and Souza de Santana Carvalho, 2022). Therapeutic centres sometimes provided transportation, but this was specific to a given service, and did not cover other types of appointments, mirroring the fragmentation in the provision of health and therapeutic services (Scott, 2020). Those living closer to large cities reported that within a city, different services were spread out, and even when services were co-located together, scheduling did not always allow concurrent appointments (Scott, 2020). The lack of reliable, accessible and affordable transportation meant that children sometimes missed appointments due to transport issues (Félix and de Farias, 2018; B. S. B. Oliveira *et al.*, 2019). Some families could not take their child to therapy at all due to lack of transport (Ambrogi, Brito and Diniz, 2021).

Mothers reported that their child had been discharged from services for missing appointments, meaning that the lack of transportation could have a significant impact on their child's access to high quality therapeutic services (Albuquerque *et al.*, 2019; Fleischer and Garcia, 2022). For others, discharge was proposed when therapists thought their child was not making sufficient progress (Scott *et al.*, 2018; Morris *et al.*, 2022). Mothers tried to address the gaps in their child's access to therapies by doing stimulation activities with them at home, but they found this challenging and wished for more instruction and supervision by healthcare providers (Junqueira *et al.*, 2020).

To address the fragmentation of services, mothers found that they had to coordinate between different services (da Silva and Silva, 2020). Communication between services and families was sometimes poor, and mothers reported experiences of scheduled appointments being cancelled without notice (Scott *et al.*, 2018). Misunderstandings and lack of knowledge about CZS also created barriers to health care, such as children with CZS being denied routine vaccinations (de Sá *et al.*, 2017).

Mothers struggled to get access to medications (Mendes *et al.*, 2020; Ambrogi, Brito and Diniz, 2021; Vale, Cândida Cordeiro and Souza de Santana Carvalho, 2022), nappies (Vale, Cândida Cordeiro and Souza de Santana Carvalho, 2022), wheelchairs (Mendes *et al.*, 2020; Fleischer and Garcia, 2022), and glasses for their child (Ambrogi, Brito and Diniz, 2021). They reported frequent stock outs of seizure medication (Ambrogi, Brito and Diniz, 2021). Insurance companies sometimes refused to authorise prescriptions or did so after a significant delay, so if the parents could not afford to pay for the medication out of pocket, the child would go without for a period (Ambrogi, Brito and Diniz, 2021; Laza-Vásquez, Briones-Vozmediano and Gea-Sánchez, 2022). Mothers also found that it was difficult to get appointments to review the dosage of medications (Fleischer and Garcia, 2022), and became even more difficult after the arrival of COVID-19 when access to services became even more limited (Valim, Marques and Lustosa, 2021).

The arrival of the COVID-19 pandemic cut off access to in-person therapies (Vilela Garcia, 2020; Vale *et al.*, 2021; Valim, Marques and Lustosa, 2021; Fleischer and Garcia, 2022). It also led to routine health appointments and specialist referrals being cancelled (Vale *et al.*, 2021; Fleischer and Garcia, 2022). Mothers were concerned that children with CZS were at high risk from COVID-19 due to their respiratory health issues (Vilela Garcia, 2020; Vale *et al.*, 2021; Valim, Marques and Lustosa, 2021; Fleischer and Garcia, 2022). Their fear and worry was compounded by the fact that their children's high-risk status was not acknowledged in COVID policy (Vilela Garcia, 2020; Valim, Marques and Lustosa, 2021). The needs of children with CZS (for therapeutic intervention, regular health monitoring and specialist follow up) were overlooked in the COVID-19 response (Vilela Garcia, 2020). Children's symptoms worsened when therapy was cut off in COVID (Vilela Garcia, 2020). The COVID-19 pandemic further exacerbated the existing challenge of transportation to therapy and health services. In some cases, transport provision that was stopped when services closed their doors due to COVID-19 didn't re-start once services resumed (Vilela Garcia, 2020). Mothers worried about the risk of COVID-19 transmission if they took their child on public transport (Vilela Garcia, 2020). COVID-19 deepened racial and SES inequalities in access to health, and the triage and

prioritisation of access to treatment for COVID-19 was predicated on ableist assumptions (Valim, Marques and Lustosa, 2021).

Barriers to education

Mothers expressed a desire for their children to receive inclusive education within mainstream schools (De Sá and Pletsch, 2021). However, they worried about sending the child to school in case the staff are unable to care for them properly (Mendes et al., 2020). These concerns appeared to be founded, as when they tried to enrol their children, mothers were told that they (or another adult) would have to accompany the child at school as the staff were not equipped to support their inclusion (De Sá and Pletsch, 2021). Children with CZS also have many absences from school due to health and therapy appointments (De Sá and Pletsch, 2021).

Perceptions of disability

Upon confirmation of a pregnancy, parents began imagining an idealised version of the baby to be, which was typically healthy and did not have any disabilities (Valim, Marques and Lustosa, 2021; Moreira *et al.*, 2022). This image was disrupted by the diagnosis of CZS, causing distress to the parents as they confronted the new reality that they had not planned for (de Sá *et al.*, 2017; Carneiro and Fleischer, 2018; Williamson, 2018, 2020; da Silva and Silva, 2020; de Melo *et al.*, 2020; Hamad and de Souza, 2020; Laza-Vásquez, Cortés-Martínez and Cano-Rivillas, 2020; Laza-Vásquez *et al.*, 2020; Mendes *et al.*, 2020; De Sá and Pletsch, 2021; Moreira *et al.*, 2022; Morris *et al.*, 2022). For many parents, the diagnosis was a shock (Félix and de Farias, 2018; Williamson, 2020), arriving late in pregnancy after earlier scans had shown typical development, or at birth (Hamad and de Souza, 2020; Morris *et al.*, 2022). Parents wanted a 'normal' child and worried that due to the CZS diagnosis their child would not be normal (Félix and de Farias, 2018; Campos *et al.*, 2020).

Parents perceptions of what CZS meant were shaped by the attitudes of the HCP who gave them the diagnosis. In many cases, the diagnosis was communicated in a curt, insensitive or callous manner (Carneiro and Fleischer, 2018; P. S. Oliveira *et al.*, 2019; Calazans *et al.*, 2020; da Silva and Silva, 2020; de Melo *et al.*, 2020; Freitas *et al.*, 2020; Hamad and de Souza, 2020; Laza-Vásquez *et al.*, 2020; Mendes *et al.*, 2020;

Williamson, 2020; Mocelin *et al.*, 2021; Marbán-Castro *et al.*, 2022). Some gave severe and alarming prognoses, telling parents that their child was likely to die or exist in a prolonged vegetative state (P. S. Oliveira *et al.*, 2019; Laza-Vásquez, Cortés-Martínez and Cano-Rivillas, 2020; Simas *et al.*, 2020; Valim, Marques and Lustosa, 2021). Some HCP used discriminatory language like "vegetable" (Azevedo, Freire and Moura, 2021; Williamson, 2024), and "hollow trunk" (Williamson, 2024). They also reinforced the message that children with CZS were not 'normal' by making statements that the child would likely never walk, talk, study, or "do anything that a normal child will do" (P. S. Oliveira *et al.*, 2019, p. 8). This reinforced a dehumanising narrative that children with CZS would not have a meaningful future or contribute to society (Williamson, 2024). The media coverage of the epidemic and reporting on the consequences of CZS added to their fear and distress, as sensationalised accounts and stigmatising images circulated (de Melo *et al.*, 2020; Tirado *et al.*, 2020; Marbán-Castro *et al.*, 2022).

Some pregnant women sought a second opinion of the diagnosis and the HCP they encountered sustained the idealised image of the expected baby, downplaying the diagnosis and creating false hope of a better prognosis (Laza-Vásquez *et al.*, 2020; Simas *et al.*, 2020). Whether or not they received a second opinion, it was common for parents to experience a period of denial (Félix and de Farias, 2018; Laza-Vásquez *et al.*, 2020; Romero-Acosta *et al.*, 2020; Dias *et al.*, 2021). While the birth forced denial to give way to acceptance, in some cases parents were only able to accept their child's physical appearance. Mothers still expected their child to be otherwise 'normal' and were in denial about their cognitive development (Laza-Vásquez *et al.*, 2020). Comparing their child to 'typical' child development milestones caused further distress, and a sense that their child would never measure up (Williamson, 2018).

Other relatives also contributed to pathologizing narratives about the child's condition (Scott, 2020). Relatives and neighbours made pitying and stigmatising comments about the child's condition to the mother (Vilela Garcia, 2020; Moreira *et al.*, 2022; Morris *et al.*, 2022). Mothers characterised these comments as 'curiosity', in a context where life experiences were expected to be shared within the community

(Ambrogi, Brito and Diniz, 2021). Others ignored or avoided the child, and by association the mother (Azevedo, Freire and Moura, 2021). Mothers formulated counter-narratives to resist discriminatory remarks, describing their child as "He is normal, he only has the microcephaly problem", which served as a way of deflecting rude questions and remarks (Ambrogi, Brito and Diniz, 2021, p. 7).

Mothers resisted these discriminatory attitudes by highlighting their child's support needs rather than dwelling on their 'limitations', insisting that they were different but not inferior (Pinheiro, 2018; Moreira *et al.*, 2022). Mothers also re-framed the argument away from their child's impairment, stressing that they were "like any other" in terms of the love they had for them (Azevedo, Freire and Moura, 2021). Mothers wanted adaptations (e.g. to the home) and assistive technology to enable their child's future participation (Williamson, 2018; Campos *et al.*, 2020). Relatedly, some parents viewed their child's disability as a social construction: a "bodily way of being in the world" rather than a biomedical state of "sickness" (Scott, 2020, pp.20). This provided another salient counter-narrative to pathologizing constructions of disability. Mothers stressed the distinction between illness and disability, pointing out that their children need therapy but are not 'sick' and cannot be cured (Scott, 2020; Vilela Garcia, 2020). For mothers, making this distinction in the face of disability stigma was a way to "give back to these children the status of individuals and humanity, emphasizing their qualities and capabilities as beings in the world" (Vilela Garcia, 2020, pp. 136–137).

Many parents, particularly mothers, invested significant time in identifying and obtaining therapeutic interventions, alternative treatments and dietary supplements that they believed could promote their child's development (Williamson, 2024). In some cases, this reflected an understanding of the child's impairments as deficiencies to be overcome through treatments, therapies, stimulation, or an as-yet undiscovered 'cure' (Félix and de Farias, 2018; B. S. B. Oliveira *et al.*, 2019; Duarte *et al.*, 2019; Campos *et al.*, 2020; Junqueira *et al.*, 2020; Laza-Vásquez *et al.*, 2020). On the other hand, Williamson finds that parents investment in attending to their child's potential for cognitive and physical

development, was "a way of asserting their children's personhood" and resisting the notion that they had no future (Williamson, 2024, p. 12).

The social identity of 'Zika mom' helped mothers to move from a narrative of personal tragedy to a situation of mutual support, demonstration of strength, and solidarity (de Melo *et al.*, 2020). By harnessing the political identity of 'Zika mom', mothers expressed a commitment to create a better future for their child (Simas *et al.*, 2020), and demand rights for their children (da Silva and Silva, 2020; de Melo *et al.*, 2020; Simas *et al.*, 2020).

Parents, particularly mothers in the role of primary caregiver, experienced disability discrimination by association (Alves *et al.*, 2023). Stigmatisation of the child's disability "results in discrimination and social exclusion of caregiver[s] in primary family environments" (Moreira *et al.*, 2022, p. 3). Parents also felt that they took on some of the social identification of the disability, through their experiences of "limitations, stigma, social struggle, demand to rights and health services" (de Melo et al., pp.10, 2020; Félix and de Farias, 2018; Scott, 2020).

Theoretical perspectives on disability

Early explanatory descriptive qualitative research on Zika and CZS had limited engagement with models or theories of disability. More recent contributions and ethnographic accounts have applied and developed disability theory to the case of CZS.

A number of studies explicitly grounded their research in the social model of disability as articulated in the UN CRPD (Mendes *et al.*, 2020; De Sá and Pletsch, 2021). They find that the biomedical framing of the Zika epidemic translated into an individual imperative to avoid infection, and this resulted in CZS being framed as an individualised medical issue as well (Félix and de Farias, 2018; Mendes *et al.*, 2020). The authors highlight the shortcomings of such a framing, and instead propose that attention must be paid to "these families' living conditions, their access to services, and infrastructure", drawing attention to the distribution of resources and societal barriers to full participation and the enjoyment of rights (Félix and de Farias, 2018; Mendes *et al.*, 2020, p. 3786). Other authors implicitly

frame disability as resulting from the interaction between impairment(s) and the physical, social, economic, and legal environment, specifically in relation to identification of external barriers (Campos *et al.*, 2020; Junqueira *et al.*, 2022; Vale, Cândida Cordeiro and Souza de Santana Carvalho, 2022; Barreto *et al.*, 2024), uneven distribution of resources (Scott *et al.*, 2018; Ambrogi, Brito and Diniz, 2021; Junqueira *et al.*, 2022), limits to full participation and strategies to overcome this (de Melo *et al.*, 2020; de Lima Nascimento Coutinho *et al.*, 2023), inclusion of disabled people (Smythe *et al.*, 2019, 2020), and human rights (Smythe *et al.*, 2019, 2020; de Melo *et al.*, 2020; Scott, 2020; Azevedo, Freire and Moura, 2021; Valim, Marques and Lustosa, 2021).

Two groups of authors theorise a relationship between body normativity[2], stigma and discrimination in the case of CZS. They find that non-normative bodies mark a person as 'other' and produce stigma, which results in discrimination against the individual (Moreira *et al.*, 2022; Alves *et al.*, 2023). Moreira and colleagues (2022) take the discussion of normativity beyond differences in bodily form and function, finding that individuals whose cognitive abilities are non-normative are othered on the basis that they are presumed to be incapable of "reason and control, tasks, and intentionality" (Moreira *et al.*, 2022, p. 9). Both find that caregivers of children with CZS also experience disability discrimination by association, and while both highlight the fact that the majority of caregivers are mothers, they do not theorise the role of gender in this process (Moreira *et al.*, 2022; Alves *et al.*, 2023).

Vilela Garcia's (2020) work is novel in its application of theories of normativity and disability discrimination to the COVID-19 pandemic response. She critiques the framing of CZS and microcephaly as abnormalities and instead proposes an understanding of CZS as part of the spectrum of variation in human form and function (Vilela Garcia, 2020). She proposes that by engaging their child in therapy and stimulation, parents aim to prevent the loss of individual capacities or 'vital norms' like the ability to swallow, and freedom from infectious disease (Vilela Garcia, 2020). She points out that all humans engage in processes, on behalf of

[2] Moreira and colleagues (2022) use the term 'body normativity', while Alves and colleagues (2023) opt for 'corpo-normativity'.

themselves or others, the promote and sustain life, and thus that the support needs of children with CZS should not be understood as 'abnormal', but simply responding to a different set of 'vital norms' (Vilela Garcia, 2020). In her analysis of the measures implemented in Brazil to limit the spread of COVID-19, Vilela Garcia (2020) finds that these measures were designed in response to the vital norms of non-disabled subjects, and as a result, children with CZS (among other groups of disabled people) were negatively impacted by pandemic measures that limited or eliminated their access to therapy and health care appointments.

Williamson (2024) extends these theorisations of normativity in a number of ways. She considers the interrelation between cognitive and physical function in the context of structural precarity through Schalk's concept of 'bodyminds' (Williamson, 2024). She finds that the capacity of children with CZS to make a meaningful contribution to society in the future is denied on the basis of their non-normative bodyminds (Williamson, 2024). She develops the concept of 'habilitative care' to describe the application of an array of technologies and activities the caregivers employ as they strive to maximise 'bodymind potential' (Williamson, 2024). She questions whether habilitative care represents an attempt to normalise the child, but finds instead that it represents "a way of asserting their children's personhood" and reclaiming their future by investing in maximising their potential (Williamson, 2024, p. 12). Importantly, Williamson shows that engagement in habilitative care work is highly gendered and understood to be part of the moral duty of a 'good mother' (2024). This echoes others who have found that demonstrating an investment in doing therapeutic activities with children at home is tied to the performance of 'good motherhood' (Fleischer and Garcia, 2022).

Williamson (2018) further theorises the interaction of gender and disability through a critical anthropological engagement with time and temporality for families raising children with CZS. She draws on the theory of "crip time" to illuminate the micro and macro rhythms of care that shape the lives of caregivers and their children (Williamson, 2018). She shows how the precarity and marginalisation faced by mostly poor, black mothers, together with the unpredictability of the child's condition and unknown prognosis produces a "difficult present" and unknowable

future (Williamson, 2018). Williamson highlights that it is through the close relationship of gendered care work that mothers come to experience crip time along with their child. In doing so, she contributes to the extension of the theorisation of crip time to include caregivers, and synthesises theorisations of gender with disability.

Finally, Williamson, Engel and Fietz (2023) explore the experiences of female caregivers during the COVID-19 pandemic in Brazil. They draw together the findings of their distinct research projects to explore the impact of the COVID-19 pandemic on disabled people and their caregivers in Brazil (Williamson, Engel and Fietz, 2023). They show that providing enabling care to a disabled relative, in the context of privatised care, minimal support from their male partners, and the suspension of services due to the pandemic, caused mental exhaustion, emotional overwhelm, anxiety and depression among caregivers (Williamson, Engel and Fietz, 2023). Drawing on the concept of debility, they develop the concept of 'dis/abling care' to describe "care that simultaneously enables others and disables caregivers" (p. 468). This contribution is unique in the application of disability theory (in this case debility) to directly explore the gendered impact of CZS on caregivers.

Conclusions of the literature review

The Zika epidemic and its aftermath have had gendered impacts, including numerous reproductive injustices, which are compounded by the intersection of gender with race, age, socio-economic status, and location. Limitations on reproductive autonomy as both a cause and a consequence of gender inequality, the gendered division of labour, and social construction of motherhood have been explored theoretically in the qualitative literature on Zika and CZS. Children with CZS face numerous forms of discrimination, ranging from social and economic barriers to full participation to the stigmatising remarks of family, friends and neighbours. Their primary caregivers, primarily mothers, work tirelessly to overcome these barriers. In the majority of the qualitative literature, disability is implicitly framed or explicitly understood as the interaction between an individual's bodily or cognitive function and the social, political, economic and legal environment they exist within, in line with the social model of disability. A smaller

number of authors have used and developed critical theory in order to better explain what disability means and how it is constructed in the specific case of CZS. In particular, authors have explored how discrimination results from the stigmatisation of the child's non-normative bodymind. Finally, Williamson offers a unique synthesis of theories of gender with disability in relation to CZS. She explores how disability shapes the gendered lives of women through the theory of crip time, how gendered norms and expectations influence mothers' engagement with habilitative care work, and how the gendered provision of enabling care in the context of precarity can be disabling (or debilitating) to the mother.

Aims

I have developed the aims of this research in response to my synthesis of the literature and review of the application and development of gender and disability theory in relation to CZS and care work. Early qualitative literature on experiences of families raising children with CZS was exploratory and descriptive and characterised by limited engagement with theory. In recent years, gender and disability have increasingly been explored theoretically in the literature on CZS and care. Very few authors have theorised how the intersection of the parent's gender and the child's disability shapes their experiences together, with the notable exception of Williamson. Qualitative research has illuminated the barriers that children with CZS and their caregivers experience, but parents' and caregivers' responses to barriers have so far received limited attention. An understanding of disability grounded in the social model, that recognises external barriers and discrimination, is apparent in the existing literature. The limitations of the social model as a framework for analysing the lives of children with CZS have not been explored in much detail. Few authors have adopted critical theories of disability in their research on CZS, and Latin American theoretical perspectives are largely absent.

In this thesis, I aim to build on Williamson's work in theorising how oppression on the basis of disability and gender interact in the context of structural vulnerability,

precarity and marginalisation. Where I aim to make a unique contribution is in the application of Latin American critical theories of gender and disability.

I also wish to build upon the work of those authors who have adopted a reproductive justice perspective in their exploration of women's reproductive decision making in light of the Zika epidemic. I will explore an aspect of reproductive justice that has received less attention: the right to raise disabled children in safe and healthy environments. In doing so I hope to demonstrate the applicability of the reproductive justice framework to the case of congenital disability beyond the decision of whether and when to have children.

Based on my analysis of the opportunities to advance existing literature, I aim:

- To examine how engaging in gendered care work in the context of societal ableism influences parents' experiences raising children with CZS and their understanding of disability.
- To understand how parents respond to barriers, navigate health systems and negotiate access to services and resources.
- To apply and develop critical disability theory through an analysis of CZS, and to bring in Latin American theoretical perspectives.
- To identify counter narratives to deficit-based framings of disability that resonate with parent-carers in the Colombian context.

Research questions

In order to address these aims, I have devised the following research questions:

- How does the intersection of patriarchy with ableism shape the experience of caring for a child with Congenital Zika Syndrome and the parental role?
- What barriers to accessing healthcare and education do children with CZS face, and how do their caregivers respond to these barriers?
- How do parents of children with Congenital Zika Syndrome understand their child's condition and conceptualise disability?

Overview of thesis

I achieved the aims of this thesis by conducting preparatory work, engaging with existing empirical and theoretical literature, and collecting and analysing data.

Preparation and background work consisted of:

- Critical synthesis and review of the existing qualitative and ethnographic literature
- Adapting the research protocol due to the COVID-19 pandemic
- Identification of gatekeepers who might be able to assist with participant recruitment
- Applying for ethical approval from the ethics committees of UCL and the Universidad Nacional de Colombia
- Planning travel and accommodation for fieldwork

Data collection consisted of:

- Writing field notes in a diary and making audio-recorded voice notes
- Participant observation and informal interviews
- Semi-structured interviews with key informants
- In-depth interviews with participants
- Group discussions with participants
- Iterative initial analysis in the field (hand coding data)

Data organisation and analysis consisted of:

- Transcription of audio recorded data and expansion of field notes
- Anonymisation and organisation of data files
- Data analysis using the constructivist grounded theory method
- Translation of excerpts into English for inclusion in the thesis

Structure of the thesis

This thesis consists of eight chapters:

- Chapter 1: Background and context

- Chapter 2: Methodology and methods
- Chapter 3: Theoretical perspectives
- Chapter 4: Care and the politicisation of motherhood
- Chapter 5: Self-management of health
- Chapter 6: Social production of disability and debility
- Chapter 7: Towards collective futures
- Chapter 8: Conclusions

Chapter 2: Methodology and methods

Setting

I conducted fieldwork for this research from February 2022 to March 2023. I conducted the majority of the fieldwork in the city of Barranquilla and surrounding municipalities in the department of Atlántico, Colombia. At the inception of this project, there was little theoretically engaged ethnographic research on Zika and CZS in the country. On the other hand, there was a robust national surveillance system and ongoing clinical research into Zika and CZS by Colombian scientists at the *Instituto Nacional de Salud* (National Institute of Health, INS) (see (Ospina *et al.*, 2020; Mercado-Reyes *et al.*, 2021; Daza *et al.*, 2022). This provided a strong foundation from which I was able to conduct my research examining the social impacts of the virus and its aftermath.

The fieldwork proceeded in three phases. The first phase lasted from February to May of 2022 and consisted of familiarising myself with the field, establishing of contacts, visiting relevant *fundaciones* (NGOs and charities) and other organisations, and interviewing key informants. The second phase lasted from June 2022 to September 2022, and involved identification and recruitment of participants, participant observation, and informal interviews. In the third phase, from October 2022 to March 2023, participant observation continued, and I also conducted in-depth, audio-recorded interviews and held group discussions with the participants. By carrying out the fieldwork in these three stages, I was able to establish a strong rapport with the participants, and to successively inquire about different aspects of their experiences, including broaching more sensitive topics later on in the period of data collection. I believe that collecting the data myself in Spanish without the aid of an interpreter also facilitated the establishment of this rapport, as I was able to engage directly with participants and reciprocate their openness by answering any questions they had about my background, the research, and my future plans.

The participants in my research were parents, carers, and adult relatives of children with Congenital Zika Syndrome. All of the children are enrolled in a cohort study called *Vigilancia de Embarazadas con Zika* (Surveillance of Pregnancies with

Zika, VEZ), conducted by the maternal and perinatal health team at the INS. The study was established in order to investigate the impact of the Zika virus on pregnancy outcomes and child health outcomes (Mercado-Reyes *et al.*, 2021). The cohort is a partnership between the INS and the US Centres for Disease Control and Prevention, who provided the funding for the study (Mercado-Reyes *et al.*, 2021). Pregnant women in Barranquilla, Cúcuta, and Cali with a laboratory or symptomatic diagnosis of Zika virus infection were identified through public health surveillance and invited to enrol in the cohort study (Mercado-Reyes *et al.*, 2021).

The cohort study team consists of clinical researchers, including paediatricians and neuro-paediatricians, a nutritionist, a paediatric orthodontist, a public health technician and two nurses. Since 2016, the team have made twice-annual visits to each study site to evaluate the children and collect data. The visits take place at a local health facility in the south of the city, usually over the course of 2-4 days. The study team contact all of the parents in advance to let them know the dates of the visit and ask them which day they will be able to attend. They create a list of expected arrivals for each day so that they know how many families will attend and can follow up if a family does not arrive. At the facility, a waiting area and consultation rooms are set up, and parents bring their child to the facility. They first complete a general questionnaire about the child's health and development, and then the children are evaluated by each specialist in turn. Lunch is provided for all attendees, which can be taken away or eaten in the waiting area. The participants travel costs to the facility are also reimbursed.

These study visits are referred to as *brigadas medicas* (medical brigades)[3] and the team have become known to the participants as *la brigada* (the brigade). The team have developed close relationships with the families in the study, keeping in touch using WhatsApp in between study visits, and providing what assistance they can beyond the official remit of the cohort study. Families often choose to stay and eat their lunch at the facility even if they have completed all of the specialist

[3] In Latin American Spanish, the expression *'brigada medica'* is used to describe a range of activities in which a team of clinicians travel to attend to an under-served patient group in a given area.

consultations, as this provides an opportunity to catch up with the staff and other participants.

I conducted key informant interviews with the study team at the INS in Bogotá and observed their visit to Barranquilla in October 2022. I also accompanied the team to the site of a related Congenital Zika Syndrome study Neiva, in Huila department, to observe a similar brigade visit that coincided with my arrival in Colombia.

COVID-19

I began my PhD in October 2020, and the COVID-19 pandemic has shaped every part of the research. I had originally intended to conduct a preliminary field visit in early 2021 to establish contacts and inform my data collection plan. This was impossible due to the risk of COVID-19 transmission and restrictions on travel. I had planned to start collecting data in October 2021 but had to delay travelling until February 2022 as Colombia was among many Latin American countries on the UK's 'red-list' and thus travel for fieldwork was not permitted by UCL. A timeline of relevant dates in the COVID-19 pandemic and response are shown in Figure 2.

The COVID-19 pandemic also shaped the data that I collected. The VEZ study visits were cancelled in 2020 and significantly delayed in 2021, and only one visit to each site took place in 2022. With the arrival of the pandemic, many in-person services were suspended indefinitely. Families were afraid that their children may be particularly vulnerable to COVID-19 infections and complications. Isolation at home and the withdrawal of services meant that access to social support was severely restricted. All of these factors meant that the families faced a new set of challenges with the onset of the pandemic, and the aftermath of the pandemic in their lives was evident during my fieldwork. I will discuss the impact of the COVID-19 pandemic in my review of the literature and in the analysis of my own data.

11th March 2020: WHO declares a global pandemic of the novel coronavirus.

16th March 2020: Colombia closes its borders.

17th March 2020: Colombia declares a state of emergency and introduces isolation measures.

23rd March 2020: First UK-wide COVID-19 restrictions begin (lockdown 1).

15th May 2020: I receive an offer of an ESRC Studentship at the UCL, Bloomsbury and East London Doctoral Training Partnership (UBEL DTP) for my PhD.

23rd June 2020: Lockdown 1 restrictions are eased.

1st October 2020: I start my PhD.

14th October 2020: Three-tier regional restriction system begins

5th November: COVID-19 restrictions re-instated in England (lockdown 2).

2nd December 2020: Lockdown 2 restrictions are eased, return to regional tier system.

8th December 2020: First COVID-19 vaccine administered in the UK.

4th January 2021: COVID-19 restrictions are re-instated in England (lockdown 3).

15th January 2021: Colombia is added to the UK 'red list', restricting travel between the two countries.

15th February 2021: Colombia receives its first doses of vaccines against COVID-19.

1st November 2021: Colombia is removed from the 'red list'.

8th February 2022: I arrive in Colombia to begin data collection.

Figure 2: Timeline of key dates in the UK and Colombian COVID-19 pandemic response. Important dates in my PhD journey are shown in italics. (eltiempo.com, 2020; Department of Health and Social Care et al., 2021; Aspinall, 2022; Institute for Government, 2022; Sherrington, 2022).

Ethics

Ethical approval

Approval for this research was granted by the University College London Research Ethics Committee (UCL REC) and the *Comité de Ética de la Facultad de Ciencias Humanas* (Ethics Committee of the Human Sciences Faculty) at Universidad Nacional de Colombia (UNAL), Bogotá.

The process of making applications to the two research ethics committees was significantly complicated by the ongoing COVID-19 pandemic, particularly in terms of the potential risk of infection to myself and the participants, and the uncertainty about the possibility of international travel. I had to significantly adapt my research protocol to allow for some or all of the data collection to be carried out remotely. I sought advice from peers who had received ethical approval for remote or hybrid data collection during the pandemic and discussed my options with my supervisors. Following these discussions, I devised a protocol that allowed for both remote and in-person data collection depending on the progression of the pandemic. I drew on existing and emerging methodological literature about the ethics, practicalities and epistemological implications of digital ethnography, online interviewing, and remote data collection methods. I received advice from researchers with experience collecting data in Colombia regarding which forms of remote data collection would be acceptable and appropriate. The proposed remote data collection methods that I selected are shown in Table 1.

Table 1: Proposed alternative methods for remote data collection.

In-person data collection method	Proposed remote data collection alternative
Participant observation	Participant daily diaries (Kaun, 2010)
In-depth interviews	Interviews via WhatsApp video call
Photovoice	Online photovoice (Tanhan and Strack, 2020)
Discussion groups	N/A

In the end, I was able to carry out in-person fieldwork as I had originally planned. With the benefit of hindsight and after collecting the data in person, I now believe

that remote data collection would have been extremely challenging. Identification of potential participants through snowball sampling was essential to building trust, and initial meetings with participants helped to build rapport. A number of key informants and participants told me later on in the research that they had initially been wary of talking to me but agreed to meet me based on the recommendation of a friend and warmed to me once we had the chance to meet and get to know each other. The participants have busy, unpredictable lives, and over the course of repeated encounters with them I had to adapt my approach to data collection so that I could enable their participation without placing too much of a burden on them. I believe that remote follow-up interviews with the same participants would be feasible and acceptable based on the relationships I have established, but I am now convinced that starting the project fully remote would have yielded very limited data.

Ethical principles

A consideration of ethical research practice has run through this entire research project. My overall ethical standpoint is grounded in feminist research ethics and participatory principles and thus centres on building and maintaining reciprocal relationships (Kingston, 2020; Bussu *et al.*, 2021). Here I will discuss a number of ethical principles became particularly salient as I conducted the research.

Informed consent, voluntary participation, and the right to withdraw are key ethical principles in all research involving human participants. In long-term participant observation, it is important to ensure that these principles are exercised at all points of the research encounter and consent given in the first meeting is not assumed to extend indefinitely (Klykken, 2022). This is both an ethical and epistemological concern. In terms of ethics, renegotiation of consent is important as dynamic power relationships between researchers and participants can influence the decision of whether to participate and what kind of knowledge to share (Sixtensson, 2021; Klykken, 2022). These power relationships can shift over time and thus consent must be considered to be dynamic and shifting as well (Sixtensson, 2021). In terms of epistemology, a single instance of 'seeking' and 'obtaining' consent assumes knowledge to be a stable entity that can be passed from one individual to another in

a transactional manner (Klykken, 2022). This is at odds with the epistemology underpinning a qualitative approach, which understands that knowledge is co-produced over time and "situated in particular relational practices" (Klykken, 2022, p. 797).

As a result of these concerns, I engaged in continual (re)negotiation of consent, ensuring that participants understood that they had the right to refuse or withdraw from data collection at any time (Shamim and Qureshi, 2013). This involved directly asking participants if they were happy to continue partaking in the research and reminding them that they were not obligated to answer any of my questions. I also treated perceived discomfort, hesitance or reluctance with an abundance of caution, taking this as a cue to remind the participant that they were not obligated to share anything with me (Shamim and Qureshi, 2013; Vanner, 2015). I believe I was able to adequately reassure them of their right to refuse. During one audio-recorded interview, a participant asked me to pause the recording while she discussed a certain topic. I made notes to help me remember where the recorded conversation left off and where we picked back up, but I have not used those notes for any other purpose, and they have not been transcribed or analysed. Other participants told me things but asked me not to write them down, and I willingly complied. Sometimes a participant would invite me to accompany them to an appointment, and then later changed their mind and said I could not come after all. I let them know that there was no problem with this, and that we could arrange a home visit or meet up outside of the home at a later date if they wanted to. It was also important to me to re-assure participants that they could still be included in the research even if their availability was limited, if they sometimes had to cancel encounters, or if they only wanted to participant in certain aspects. Almost all potential participants I contacted expressed enthusiasm about the opportunity to share their story with me, but for some their life circumstances made this challenging. Upon initial recruitment many participants assumed that they would need to meet me at my home or at a clinic at set times, so I reassured them that I could visit them at home or a convenient location for them, and that my schedule was flexible so that they could decide the timing and duration of our encounters.

In terms of continually negotiating informed consent, beyond the initial explanation of the participant information sheet and opportunity to ask questions I informed participants of topics I intended to address in follow-up interviews in advance, and again used this as an opportunity to remind them that it was okay to skip a question or pause or terminate the interview at any time.

Transparency about my positionality and role was also important to ensuring that participants were making an informed decision about what information to share with me, if any. Participants asked me lots of questions about my background and the research, and I answered them honestly. On the personal side, participants asked me whether I was married or had a boyfriend, whether I had children, whether I still lived with my parents back in England, whether I was religious, whether I missed my family, and what I thought of Barranquilla. Regarding the research, they asked me about what doing a PhD involved, whether I made notes in English or Spanish, how long it would take to write my thesis, what I would do after finishing the research. I welcomed their questions and answered them honestly. Based on the background information they had learned about me, participants sometimes said things to the effect of "when you have children you will see…" or "the thing about being married is…". I believe that sharing information about my background and personal life helped them to decide which topics to discuss with me and how to frame them.

Transparency is closely related to another important ethical principle in my research, that of reciprocity. The participants in my research were very open with me and talked to me about many sensitive topics, traumatic experiences, and challenging circumstances they had experienced. As I have already outlined, I reciprocated by answering questions that the participants had for me and sharing details of my background and personal life. Participants often used photographs to help them tell a story, and I also showed them photographs of my family home, the neighbourhood where I lived in London, and my family members.

Another topics more directly implicated in reciprocity is reimbursement. I considered the possibility of monetary reimbursement for the participants time and sought advice from the literature and more experienced researchers to help me

decide whether this was appropriate. The decision of whether to pay participants must be made based on an analysis of the specific research context (Goodman *et al.*, 2004; Cajas and Pérez, 2017). Through discussion with an anthropologist with a decade of ethnographic research experience in Colombia, I decided that the risks of offering monetary reimbursement to participants outweighed the potential benefits. Additionally, the risks would mainly be to the participants. I believed that offering financial compensation to participate may complicate the issue of consent and could inadvertently create a coercive influence, compelling potential participants to enrol against their better judgement in pursuit of reimbursement (Goodman *et al.*, 2004). Rapport and trust between researchers and participants is important in all research but is particularly central to ethnographic data collection. I believed there was a risk that introducing a financial dimension to the relationship could undermine this (Cajas and Pérez, 2017). Monetary reimbursement also had the potential to distort the data I was able to collect, as participants might have felt compelled to tell me what they thought I wanted to hear in order to ensure that they would be paid. I also believed that financial compensation for participants had the potential to cause suspicion, distrust, or jealousy among the wider community.

In practice, I found that indeed offering monetary reimbursement would have been inappropriate, though for slightly different reasons that those that I had anticipated. Separately from the issue of reimbursement for their time, I was committed to making sure that participants did not incur any financial costs of participating in the research. This meant that I paid for our food and drinks if we met in a café and offered to reimburse any travel or other incidental costs they incurred in the course of their participation. Most participants were reluctant for there to be any financial dimension to our relationship, and refused my offers, particularly earlier on in the research. Over time as we built more rapport, most participants became more open to accepting reimbursement and letting me pay for refreshments. In Barranquilla, it is customary that whoever proposes the meeting or invites the others pays the bill, and when I framed my offer in this way it was more acceptable to the participants. When I accompanied *la brigada* on their visits to the study sites, I saw that they provided lunch and refreshments to all participants. I also learned that they had received sponsorship from a company, which was provided in the form of baby

wipes and nappies for the children. Each family was given a large bag of supplies to take home, as an token of appreciation for their continued participation in the cohort study. Based on my observations of *la brigada,* and the fact that participants favoured in-kind reciprocation to monetary compensation, I saw an opportunity to offer recognition of the participants contributions in the group discussions. At these events, I provided lunch and refreshments and a gift bag for each family containing personal care items like shampoo, baby wipes, hand soap, flannels, as well as biscuits and snacks. I also hired a pair of university students to help entertain the children so that their mothers could engage in the discussion and brought toys and art supplies for the children to use. The participants accepted and appreciated this form of reciprocation for their participation.

Key informants

I identified some key informants ahead of my arrival in Colombia and established many more contacts while in the field.

Academics

I identified the maternal and perinatal health research group at the INS as potentially important contacts through a report of their work that was published by the Social Innovation in Health Initiative (Bautista-Gomez, Agudelo and Castro-Arroyave, 2020). I reached out to Dr Marcela Daza, a neuro-paediatrician in the team, by email to introduce myself explain the aims of my research. One I arrived in Colombia, I visited her at the INS in Bogotá, where she shared more details of their completed and ongoing research on Zika and CZS. I explained more about my research and asked if she might be able to help me with identification of potential participants, which she confirmed. I conducted a follow-up recorded interview with Marcela later in the year, via video call from Barranquilla. I accompanied the team on two study visits, one to Neiva in February 2022 and one in Barranquilla in October 2022.

On the advice of a contact who I met during a training event, I made contact with members of the Zika Social Sciences Working Group of the WHO ZIKV Individual

Participant Data Consortium (ZIKV IPD Consortium, 2021). I attended their online meetings from November 2020 – June 2021. This helped me to gain an understanding of the context of researching CZS in Colombia, particularly during the COVID-19 pandemic.

NGOs

Before travelling to Colombia, I tried to identify NGOs working in the field of disability, with parents, or on gender equality and empowerment in Barranquilla. I identified some organisations through Facebook, but their online information was frequently outdated which made contacting groups challenging. I had more success identifying and contacting local organisations once I was based in Barranquilla, including through social media. I found out about events by following the social media profiles of the local ministries for health; education; women, equity and gender; environment; and economic development. One such event was IncluExpo, an event hosted by the *Gobernación del Atlántico* (Departmental Government of Atlántico) at which different NGOs in the field of disability set up stands and exhibited their work. This proved to be an excellent networking opportunity, and I established several contacts who went on to become key informants in the research. As I became more familiar with the kinds of key words that organisations used in their promotional materials, I was able to continue identifying other groups using social media. I identified further key informants through word of mouth and referrals from existing contacts. Interviewing NGO staff provided a useful foundation for understanding how disability is discussed and understood in the region, and they kinds of support available to families. One particularly influential key informant was Connor, the director of an NGO focused on providing free legal advice to people with disabilities and their families. In addition to his role in the NGO, Connor was the secretary of his local neighbourhood action committee, and he facilitated meetings with many other community leaders.

Juntas de Acción Comunal

A key source of information in the familiarisation phase of the research were the *Juntas de Acción Comunal* (Neighbourhood Action Committees, JACs). Committee members are typically *lideres sociales* (community leaders), and they act as liaisons between the community and the local government. I attended JAC meetings and met with leaders in different *barrios* (neighbourhoods). This helped me to familiarise myself with the city, current events, and the pressing issues facing the population. Through these discussions I also came to understand the level of awareness and engagement with disability among those outside of the NGO field. Discussions with the JAC members were a good opportunity to learn more about discourses and language around the topic of childhood disability and infectious disease.

These meetings took place all over the city, and as such provided a good opportunity for familiarisation with the field site. I learned how the public bus system worked and got to know the characteristics of different localities and neighbourhoods. I learned which areas were less secure for me to visit on my own and received lots of advice on personal safety and security from Connor and other JAC members I met. This familiarity with the city and ability to take care of myself proved to be important in building rapport and making plans to visit participants later on. At first many participants assumed that I had not travelled beyond the wealthy neighbourhoods in the north of the city, and that I would be unwilling to visit them at home out of concern for my personal safety. They were reassured when I explained that I had attended meetings across the city, was familiar with the public transport system, and had been advised by community leaders about personal safety.

Sampling

The intended participants for this research were parents and other carers of children with CZS in Barranquilla and the surrounding municipalities. This field site was selected due to the relatively high prevalence of Zika infection during the epidemic of 2016 - 2018, robust epidemiological surveillance for Zika and CZS by the

Secretaria de Salud de Barranquilla (Health Secretary of Barranquilla), and the fact that Barranquilla was a study site for the VEZ cohort study.

Identification of the participants

The INS clinicians helped me to identify potential participants. Dr Marcela Daza in particular offered to share information about my research with mothers whose children were enrolled in the VEZ study via WhatsApp. I designed a flyer based on the participant information sheet for the research and included my contact details and a photo. Marcela gave me feedback on the wording of the flyer, pointing out terms that might be unfamiliar to the participants and suggesting edits to the text that helped it to read more naturally. The final flyer is shown in Figure 3. I had hoped that Marcela would share the flyer with all of the families in the cohort. However, she suggested that she share it with a particular mother, Rita, who was well-connected to the other families.

Marcela thought that Rita would be keen to participate and could also help me to identify and recruit other families. Rita helped me to identify three further participants, Daniela, Patricia, and Alba, who she was in regular contact with.

Invitación a participar en una investigación cualitativa

¿Qué es la investigación?
La investigación es una exploración de los aspectos sociales del virus de Zika y microcefalia/ síndrome congénito de Zika. Espero aprender cómo es ser una mamá, papá o cuidador de un niño o una niña con microcefalia y/ o otros condiciones causadas por el virus de Zika. Quiero entender como tú, algunos otros cuidadores y tu comunidad entienden la condición del niño o niña. También quiero aprender que fortalezas ustedes tienen y que desafíos enfrenten en el cuidado al niño. Mi objetivo es que los resultados de la investigación se utilizarán para mejorar políticas publicas y aumentar el acceso a recursos para familias con niños y niñas con discapacidad.

¿Quién es la investigadora?
Me llamo Rose, soy investigadora doctoral del campo de la Salud Global, con un enfoque de temas de género y discapacidad. Soy de Londres, Inglaterra, y tengo 27 años. Estoy aquí en Colombia para investigar las experiencias de las familias de niños y niñas afectados por Zika. Eso lo haré en manera etnográfica - la cual se centra en entender las experiencias de la vida cotidiana de los individuos y permite así comprender mejor las prácticas sociales existentes. Voy a quedarme en la ciudad de Barranquilla hasta el diciembre de 2022.

¿Qué actividades comprende la investigación?
Me gustaría pasar tiempo contigo y los miembros del hogar. Esto me permitirá observar sus actividades cotidianas y hablar con ustedes en una manera informal. Además me gustaría hacer entrevistas mas formales. No voy a realizar ninguna actividad médica. Puedes decidir cuanto tiempo pasamos juntos.

Quiero saber más…
Si estás interesado en participar, por favor, avísame. Puedes dar tu permiso a la Dra. Marcela a compartir tu numero de celular/ WhatsApp conmigo, o me puedes contactar directamente por WhatsApp, Facebook, o correo electrónico. El siguiente paso será que nos reunamos para que yo pueda explicar el proyecto con más detalle, y tu puedas hacerme cualquier pregunta que tengas. Después de esto, si aún deseas participar, le pediré que firme un formulario de consentimiento.

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Esta investigación tiene aprobación ética de los comités de éticas de la University College London y la Universidad Nacional de Colombia.

Figure 3: A flyer containing information about the research for potential participants.

Patricia in turn shared details of the research with Hilaria. They hadn't seen each other in some time but were friends on Facebook. I used the flyer to share information about the research and my contact details with potential participants.

When the brigade came to Barranquilla later in the year, I attended the clinic to observe their activities. I also introduced myself to attendees who I had not met, gave them information about my research, and invited them to participate. Veronica, Andrea, Beatriz and Paula all shared their contact details with me, and they all agreed to participate. I was in touch with Paula for several months and we made plans to meet, but she cancelled at the last minute. She also cancelled the re-scheduled meeting, which I took that to mean she was no longer interested in participating. Veronica had come to the brigade visit in place of her sister Catalina, so she referred me to her. Andrea shared my details with Julia, a mother from the brigade group who she had got to know well as their sons attended the same therapy centre. Figure 4 shows the process of snowball sampling. The challenges and limitations of this sampling method are discussed later in this chapter.

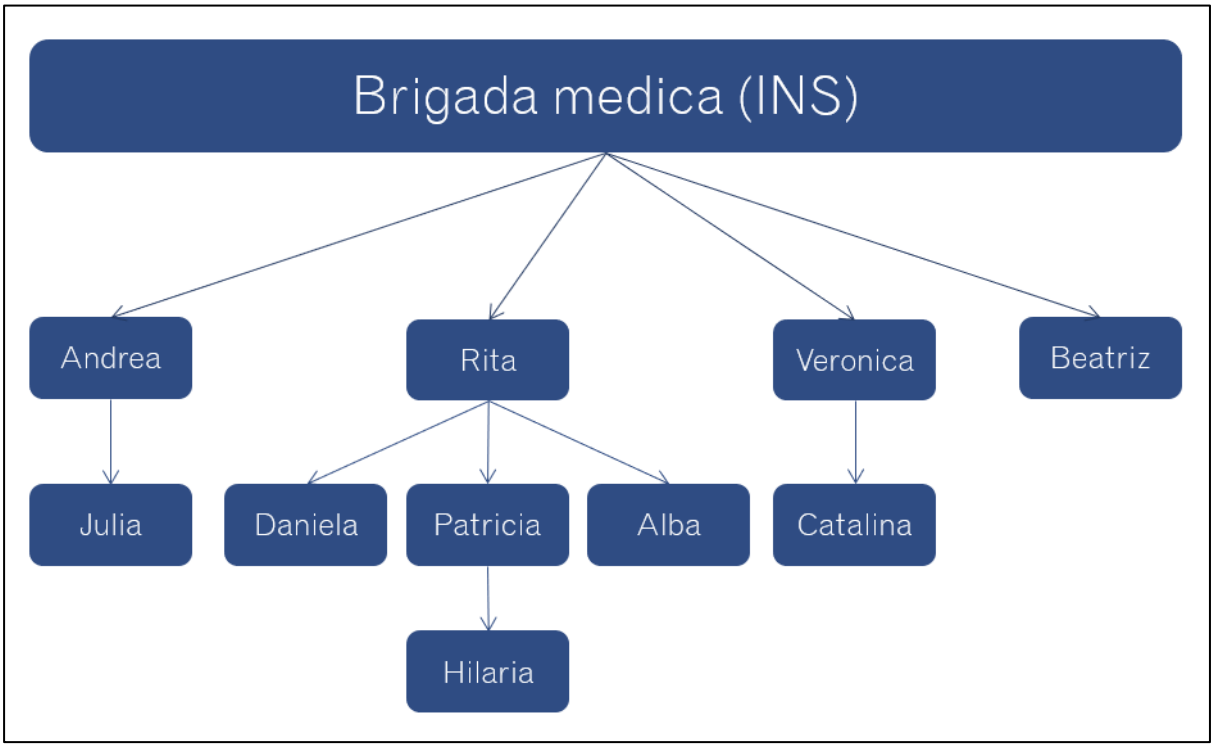

Figure 4: Diagram showing the process of identifying participants and snowball sampling.

Recruitment

Recruitment to the research took place during an initial meeting with the potential participant. Sometimes this took place at home, and other times at an outside

location, usually a café. I used these meetings to introduce myself, get to know the potential participant, and explain the research. The potential participants that I was referred to through snowball sampling were usually quite keen to participate as they wanted an opportunity to tell their story. Given that I was recruiting participants through an existing clinical cohort study, I explained that I was interested in the social aspects of their experience, such as their access to health care services, experiences taking their child to therapy sessions, family relationships and daily activities. By giving this explanation, I tried to distinguish my research from that which they were already involved in and give them an insight into the type of questions I would like to ask them in the future.

After giving a more informal verbal overview of the research, I presented the participant information sheet and sought their consent to participate. The participant information sheet was usually well understood by the participants upon reading it, though the language of the Data Protection Statement provided by UCL REC caused some confusion. In response to this and any other questions they had, I explained the information further, putting it into different words to help them understand. Once they had read and understood the participant information sheet and I had answered their questions, I verbally asked participants if they were interested in participating in the study. If they said yes, I proceeded to seek their informed consent to participate using the informed consent form. Again, this was generally well understood, though participants commented that the form was very long, and some parts seemed repetitive to them. After participants gave their consent to participate if there was still time left in that initial meeting, I usually asked them to give some background about them and their family. Whenever possible before leaving that meeting I would try to schedule a home visit or to accompany them to an appointment, in order to begin conducting participant observation.

Participants

A total of nine families participated in this research. The mother-carers were the primary participants in the research. Table 2 shows the demographic characteristics of each family. All names are pseudonyms. The majority of the

participants lived in the metropolitan area of Barranquilla and Soledad. Each *barrio* (neighbourhood) is assigned to a socio-economic strata (SES) by the *Departamento Administrativo Nacional de Estadística* (Department of National Statistics DANE). The determination of SES is based on an assessment of the quality of the dwellings and surroundings in the neighbourhood (Cantillo-Garcia, Guzman and Arellana, 2019). Strata 1 indicates the lowest SES, and 6 the highest. Most of the participants lived in barrios in strata 1 and 2. The map in Figure 5 shows the approximate location of each family home, and the corresponding neighbourhood level SES.

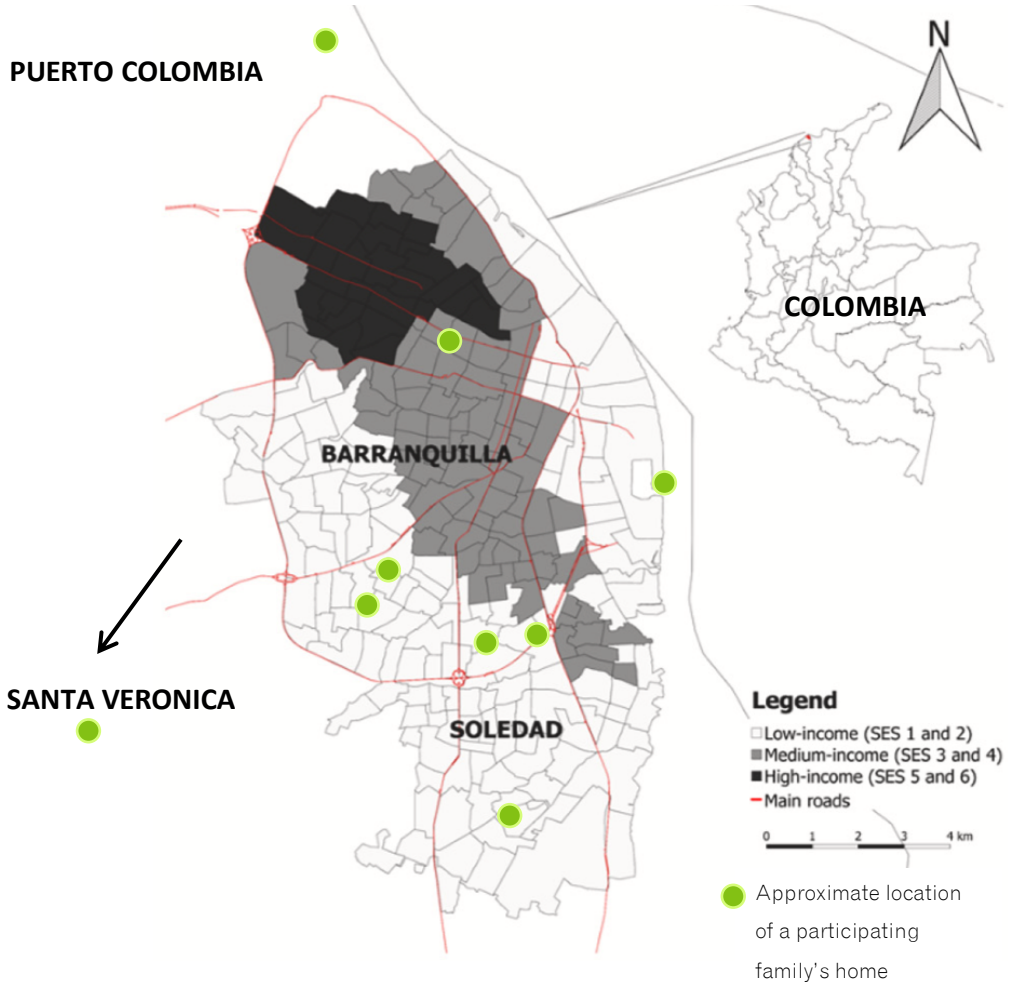

Figure 5: Map of Barranquilla including neighbourhood level socio-economic strata information and the approximate location of each participating family's home. Adapted from (Arellana et al., 2021).

Table 2: Household and demographic characteristics of participating families.

Mother	Father	Marital status	Children	Other adults	Mothers race	Nationality	Locality	Barrio SES
Rita	Jaime	Separated	Teresa **Lola**	Alejandra (Rita's sister)	Mestiza	Colombian	Soledad	1
Daniela	Andres	Married	**Eduard** Sergio	N/A	Mestiza	Venezuelan	Soledad	1
Patricia	Umberto	Separated	Simon **Dalia**	Selina (Patricia's sister)	Afro-descendent	Colombian	Sur Oriente	2
Hilaria	Justin	Married	Bella **Máximo** Matias	Ramiro (Justin's brother)	Mestiza	Venezuelan	Sur Oriente	1
Alba	Oscar	Married	Cristian **Liliana** Rodrigo	N/A	Afro-descendent	Colombian	Metropolitana	1
Andrea	Jorge	Married	**Maurice**	N/A	Mestiza	Colombian	Riomar	3
Julia	Arturo	Married	Alicia **Stefano**	N/A	Mestiza	Colombian	Metropolitana	1
Catalina	Vincent	Married	**Dominic** Alberto Juan Carlos Nicolas	Veronica (Catalina's sister)	Mestiza	Colombian	Puerto Colombia	N/A*
Beatriz	Tiago	Married	**Joshua**	N/A	Afro-descendent	Colombian	Juan de Acosta	N/A**

Children are listed in descending age order, with the names of children with CZS in bold.
*Currently under assessment.
**Living in on-site accommodation provided by Tiago's employer.

Other relatives participated in the research in addition to the mother-carers. All of the women who were married were living with the father of the child with CZS. In recruitment, I was put in contact exclusively with mother-carers. In some cases, I was able to speak with fathers, and in others it was not. I was unable to visit Julia and Alba at home due to insecurity in their neighbourhoods, and as a result, I did not have the opportunity to meet Arturo or Oscar. I visited Andrea at home, but Jorge's working hours meant that I did not meet him either. In these families, the mothers were the primary caregivers to the children and took care of the home.

On the other hand, Justin worked repairing household appliances, and in between jobs would frequently return to the home with his younger brother Ramiro to spend time with his family. He was very affectionate with all of his children and keen to talk to me about their family life. When I arrived for one planned visit, both he and Hilaria were dressed in their house clothes cleaning the apartment. While Hilaria took responsibility for taking Máximo to therapy, Justin took them to appointments on the back of his motorcycle when he was not working, and also picked up groceries and cooked for the family. I interviewed Justin and Hilaria together.

I met Andres at a birthday party thrown by Rita, and it was apparent that he, Daniela and their sons were a close knit and affectionate family. Daniela and Andres were both working in informal jobs while they waited for their permission to remain in Colombia to be granted. I was unable to visit Daniela at home, and Andres had ongoing health issues, and as a result did not have any further opportunities to speak with him.

Rita had been separated from Jaime for a number of years, and had limited contact with him, so I did not meet him. During the period of my data collection, Patricia and Umberto separated, though they remained living in the same apartment. Initially, Umberto spoke to me when I visited the house, and I accompanied him when he took Dalia to a therapy session. Over the course of my fieldwork, the couple became more distant, and Umberto spent more time away from the house. When they were in the house together, the atmosphere was uncomfortable. I considered seeking out an interview with Umberto, given that he was one of only a few fathers I

had the opportunity to meet, but ultimately decided that doing so might threaten the rapport I had developed with Patricia.

Tiago and Vincent were both present when I visited Beatriz and Catalina at their homes, and they entertained the children while I interviewed the mothers. They both tended to defer to their partners on matters relating to the children, and did not speak to me much at all. Catalina told me that since Vincent had retired, they shared the housework and childcare equally. In contrast, Beatriz took primary responsibility for Joshua's care. Like Justin, Tiago's job had irregular hours, so he spent more time at home with the family during the day. Tiago played with Joshua, and would drop him and Beatriz off at the bus stop on his motorcycle if he was not at work when they had to go to an appointment.

As shown in Table 2, a number of children in this research lived in households with other adults beyond their parents. Three of the mother carers lived with their sisters (their children's aunts), Rita and Patricia under the same roof and Catalina in an adjoining apartment. The three aunts all consented to participate in the research and contributed to differing extents. Veronica accompanied Catalina to the brigade visits and group discussions. Selina and Alejandra were both employed outside the home, but spoke to me on occasions that I was visiting while they were home from work. Justin's brother Ramiro lived with him and Hilaria, but usually stayed in another room when I was visiting the home.

Relationship between participants

The participants in this research were introduced to one another through their participation in the VEZ cohort study. They have become friends, and many of them have stayed in touch in between cohort study visits. Some of the children also have therapy centres and schools in common. During the early cohort study visits, the INS staff observed that the women were becoming friends and supporting one another. With the encouragement of the staff, the mothers started to discuss the possibility of starting a *fundación* (grassroots organisation) to raise awareness of CZS and lobby for better access to services for their children. In 2019, a group of the mothers involved in the cohort study devised a logo, set up a Facebook page, and

got t-shirts printed in the name of *Fundación Ángeles sobre Ruedas* (Angels on Wheels). They held an awareness raising walk on World Microcephaly Awareness Day (30th September 2019), and organised seasonal social events in the autumn and winter of that year. They intended to legally formalise the organisation and begin fundraising, but these efforts were cut short by the start of the COVID-19 pandemic in early 2020. Contact between the families was very limited for the following 18 months, and the cohort visits were curtailed in this period as well. This period of isolation, combined with the broader impacts of the pandemic on the families, put an end to the group's efforts to formalise the *fundación*. During the period of my data collection, some of the mothers began discussing the idea of starting a new *fundación*. This will be discussed in chapter 7.

Extent of the children's impairment

The children in this research have different degrees of impairment. Alba and Beatriz were both infected with Zika in the final months of their pregnancies, and as a result, Liliana and Joshua were less affected by the virus. They can both walk, talk, feed themselves (provided the food is soft or has been cut into small pieces), and use the toilet with assistance. Liliana attends a school at an integrated education and therapeutic centre for disabled children. Joshua is enrolled in a local school, however their inclusive education provision is poor and the school requires that Beatriz stays to assist Joshua in the classroom. As a result, his attendance is very limited.

The other seven mothers were infected early in their pregnancies, and the resulting impairments in their children were more profound. Their children (Lola, Eduard, Máximo, Stefano, Dalia, Maurice and Dominic) require assistance to sit up and reposition their bodies. They need chairs, padding, straps and other devices to maintain their position and posture – the most common device sought for this purpose is a *coche neurológico* – a padded, specialised wheelchair with head and neck support, straps for the body, and a footrest. They need to be fed and encouraged to chew their food, and Maurice had a feeding tube as he is unable to chew or swallow. They are incontinent, and either unaware or unable to communicate that they needed to urinate or defecate, so they use nappies. Dalia is

the only child of this group who communicates by making sounds, such as grunting and grinding her teeth. Lola, Eduard, Máximo, Stefano and Dalia all respond to the sound of their mothers' voices and other sounds, usually by looking over, smiling or laughing. Dalia is able to attend a local school accompanied by an assistant and receive inclusive education. Some of the other children have been enrolled in specialised or mainstream schools for short stretches, but the level of support that they need in order to participate is seldom available, and as a result, none of them have consistently attended school.

Initial meetings

In the first few recruitment meetings when I asked the participants to share some detail about their family, most of them shared a lot of detail about their child's clinical history. They showed me documents related to their child's diagnosis and care, the most important of these being *la historia clínica* (clinical history document). It seemed to be important to them to share these details, as most participants brought them up organically without any prompting from me. It also felt to me like a good exercise to establish rapport and set the tone of the research relationship. The participants spoke authoritatively using medical terms and established themselves as experts on their child's condition. I was able to validate their expertise by asking questions and expressing my genuine interest in the information they shared. I began to use this time at the end of the first meeting, or the next meeting after that, to ask participants directly about their child's clinical history. This provided useful background for future encounters and helped to establish rapport. I used my field notes from these early discussions to draft follow up questions. Some of these I developed further into interview questions, and others I kept at hand to use in participant observation if the conversation reached a lull.

In subsequent visits having collected this data on the clinical history I was able to bring the conversation around to the social aspects of their experience. Again, I was led by what the participants told me and the topics they raised in conversation. Access to health, education and therapy services were key concerns. They talked

about this in terms of their struggle to gain access on behalf of their child, and the rights that their children had to access these services. I adopted these ways of talking about the social impact of Zika and CZS when explaining my research to newly recruited participants, and this seemed to help them understand the distinction I was making between the clinical cohort study they were participating in, and my research.

Methodology

In this research I bring together critical ethnography with constructivist grounded theory for the overall methodology. My theoretical stance is informed by critical theory, particularly Latin American theories of coloniality, gender and disability. In terms of my political stance towards the research, I am orientated towards critique of oppressive systems and action informed by the needs of those who are most affected.

Ontology and epistemology

In line with the interpretivist ontological stance, I understand meaning and social reality to be constructed through the relationships between events, objects and people (Hair and Clark, 2003). I believe it essential to consider these relationships in their specific historical and material context, and to interrogate the power dynamics that shape the construction of our social world (Hair and Clark, 2003). In terms of epistemology, I adopt an "activist stance" within a social constructivist outlook, positioning myself as a critical participant in the co-construction of emancipatory knowledge (Dutta, 2014; Fine, 1994, pp.23).

Inquiry grounded in this critical, interpretivist worldview is well served by the use of critical ethnography and constructivist grounded theory as methodologies (Hair and Clark, 2003; Charmaz, 2017). Critical ethnography serves as a method for putting critical theory into action, while constructivist grounded theory provides a set of tools for conducting research on power and inequality (Madison, 2005; Charmaz, 2017).

Critical ethnography

Critical ethnography aims to contribute to social justice and the advancement of knowledge that "privileges the perspectives of those who have been subjugated" (Alonso Bejarano et al., 2019; Davis and Craven, 2016; Dutta, 2014, pp.5; Madison, 2005). Structural inequalities shaped the course of the Zika epidemic, and the response failed to account for and protect reproductive and sexual rights and the rights of women and people with disabilities. The public health response to Zika reinforced the status quo with regards to the gendered division of labour and the social exclusion of people with disabilities. Critical ethnography seeks to propose empirically grounded interpretations of events that "unsettle" the status quo "by bringing to light underlying and obscure operations of power and control" (Madison, 2005, p. 5; Fassin, 2013, p. 125; Norander, 2017). With this in mind, my aim was to work with participants to understand how structural inequalities shaped the experience of raising a child with CZS.

While early ethnography extracted data from people and cultures of the Global South in the service of the colonial project, critical ethnography aims to interrogate and dismantle its own coloniality and contribute to the decolonisation of research (Alonso Bejarano *et al.*, 2019). Critical theory, particularly that of decolonial feminism and Latin American critical disability studies, underpins my understanding of the structural inequalities shaping the Zika epidemic, response, and aftermath. Critical ethnography is a suitable methodology for bringing together critical theory with lived experience to deepen our understanding of and enable the dismantling of structural inequalities (Madison, 2005). The theoretical stance that informs my use of critical ethnography will be outlined further in Chapter 4.

Within critical ethnography, I position my work as a feminist ethnography. Power is a central concern in feminist ethnography, and rather than focusing on women's lives, feminist ethnographers strive to make visible the ways that the social structure of gender shapes everyday lives and intersects with other structures (such as race, disability, and socio-economic status) to produce marginalisation (Davis and Craven, 2016b). In terms of knowledge production, feminist ethnography

draws on feminist theory, and aims to produce knowledge that serves the needs of the communities and participants being studied (Davis and Craven, 2016b).

Reflexivity is a guiding methodological and ethical principle in critical feminist ethnographic research (Fine, 1994; Madison, 2005; Norander, 2017). Key to the reflexive approach are considerations of positionality and subjectivity. Transparency about researcher characteristics and background is necessary but not sufficient in critical ethnography. In order to be meaningful, the researchers positionality and subjectivity must be considered in relation to that of the participants, topic being studied, and the overall research process (Madison, 2005; Norander, 2017). Reflexivity (comprising of the overlapping dimensions of the researcher's positionality, motivation, affect and reciprocal relationship to the research) has been a central concern in the design and conduct of this study, and is discussed in more depth later in this chapter (Davies, 2007; Reid *et al.*, 2018; Dodgson, 2019; Lemos Dekker, 2019; Subramani, 2019).

Constructivist grounded theory

In order to provide structure to the data collection and ensure systematic analysis, I draw on aspects of Charmaz's constructivist grounded theory methodology (Charmaz, 2006). The emergent, inductive method of constructivist grounded theory provides a way of doing critical, reflexive qualitative inquiry (Charmaz, 2017). It requires the researcher to ask critical, challenging questions not only of the data but of themselves and their relationship to the research process (Charmaz, 2017). The open-ended nature of constructivist grounded theory inquiry requires the researcher to interrogate their own preconceived ideas in order to gather rich data "that do not undermine or demean respondent(s)" (Charmaz, 2006, pp.33). Simultaneous data collection and analysis enables the researcher to develop a nuanced understanding of the meaning of the data (Charmaz, 2006). In this research, I conducted simultaneous data collection and analysis, and iteratively developed the data collection tools based on initial interpretations of the data.

Over the course of my doctoral research, my approach has become increasingly aligned with critical medical anthropology. I am situated within a global health

department, and felt that in order to confidently place my work in dialogue with both fields I needed to adopt a structured approach to analysis. Drawing on a well-documented and systematic approach such as constructivist grounded theory will enable me to report on my research with transparency and comply with guidelines (e.g. COREQ and SRQR) for reporting qualitative studies when submitting journal articles based on this work to global public health journals (Tong, Sainsbury and Craig, 2007; Blignault and Ritchie, 2009; O'Brien *et al.*, 2014).

Data collection methods

In critical inquiry underpinned by decolonial theory and a concern for social justice, the selection of appropriate methods is a primary concern, since "methods of gathering data can either give or deny the researched the authority to speak from their perspective" (Chilisa, 2020a, pp.240). Aligning the chosen data collection methods with the overall methodology is also key to producing rigorous research findings. I used multiple methods of qualitative data collection in this research – participant observation, in-depth interviews and group discussions. The use of a range of data collection methods enabled me to triangulate the data, deepening my understanding of the topics being discussed and offering opportunities to test my initial interpretations of the data (Birt *et al.*, 2016).

The use of multiple methods was also a practical choice, as some participants had limited capacity to participate, but still wanted to share their story. By offering them different ways to contribute I was able to include a wider range of voices and experiences. Alba was six months pregnant when I first met her in July 2022. She agreed to participate, and initially said that I could come to her home to conduct participant observation with her and Liliana. She informed me that it would be dangerous for me to be out on my own in her neighbourhood, as I would stand out as a target for harassment, pickpocketing, or robbery. We agreed that this safety risk could be overcome if I arrived by taxi and waited in the car until Alba came down from the apartment to meet me. However, she experienced some health problems during her third trimester and found it difficult to get up and down the stairs. Her husband was working away for weeks at a time, so there was not another

adult in the house who could collect me when I arrived. We agreed to wait until after the baby was born and re-assess the situation then. Alba gave birth in September, and she and her husband started looking for somewhere new to live that would have more space for their growing family. When we re-visited the idea of me visiting her at home, she said that the apartment was too crowded, and it would be better if we waited until they were able to move. It took them several months to find a suitable new home, and as a result I was not able to visit them at home within the period of fieldwork. However, Alba came to all three group discussion meetings. For her these were more convenient as they took place out of the home, so the crowded apartment was not an issue, and Alba did not feel responsible for my travel and safety. The group discussions were also an opportunity to socialise, and as childcare was provided, she could attend with all three children even when her husband was away. The meeting venue had a bathroom with baby changing facilities and a private room where Alba could breastfeed her baby. In Beatriz's case, she lived in a very remote area around 1.5 hours from Barranquilla by bus. The family owned a motorcycle, but Beatriz's husband used this for work. Beatriz had to stay at school with Joshua during the day three days per week, and take him to therapy on the other days. Joshua's CZS manifests mostly in cognitive and behavioural symptoms, and when his routine was disturbed he became distressed, and could be impulsive and aggressive at times. Beatriz suggested that I visit her at home where we could conduct a recorded interview. This was less disruptive to their routine, and thus more feasible than longer-term participant observation. Beatriz also attended one group discussion and brought Joshua, however he found the long journey and group environment overwhelming and became upset, so Beatriz's ability to participate in the discussion was limited.

All data collection was carried out in Spanish. Before commencing data collection, I spoke Spanish to an upper-intermediate level, and had focused my language learning on Colombian Spanish in particular by engaging in one-to-one online classes with Colombian teachers. Over the first phase of the research engaging with key informants and attending community events helped me to improve my confidence, fluency, and comprehension, as well as familiarise myself with the *Barranquillero* accent and local colloquial words and phrases.

Participant observation

The majority of the data was collected using participant observation with participants at their homes, clinics, therapy centres, and also at community events and public meetings. Participant observation formed the backbone of my long-standing relationships with the participants and their families. Repeated engagements over a prolonged period enabled me to get to know the routine activities and social dynamics of the families and observe developments in their circumstances over time. I conducted participant observation with families of children with CZS to develop experiential knowledge and understanding of daily activities related to childcare, household chores, therapeutic activities and health care seeking, and to observe the unspoken practices of family life such as the gendered division of labour (Fals Borda, 1987; DeWalt and DeWalt, 2011). Participant observation typically involved spending time with the mother and the child with CZS at home or accompanying them to a clinic or therapy centre. At their homes, other family members were often present – fathers, siblings, aunts, and grandparents. Some families lived in close proximity to other relatives, so aunts, uncles and cousins also came and went during my visits. During these visits, I talked to the mothers and participated in their daily routines of getting children up, bathed and dressed, feeding, and entertaining them. Sometimes health or education professionals visited them at home, and where possible I timed my visits to coincide with theirs so that I could observe their interactions with the family. If the child had a medical appointment booked, I asked to accompany them, and sometimes they also spontaneously invited me to attend. I recorded my observations in a field diary and using audio recorded voice notes which I later transcribed.

The participants lives were busy, and their children's condition could be unpredictable. For these reasons, plans frequently changed. The flexibility of participant observation became a real asset as I was able to continue collecting data even when things did not go quite as expected. One morning I arrived at Patricia's house to spend the day with her and her daughter Dalia. Patricia had invited me to visit them that day as she knew her husband would be out at work –

they were in the process of separating, and she felt that she would be able to speak more freely without him there. When I arrived, Patricia and Dalia were still wearing their pyjamas and neither had eaten breakfast. It turned out that Dalia had been up in the night with a sore throat. She was tired, grumpy, and had refused to eat her usual breakfast of eggs and *arepa* due to the pain. With her husband and sister both out at work, Patricia had tried to enlist the help of her sister's boyfriend to bring the ingredients for her to make a soup for Dalia, but he had not replied to her messages. Without another adult around, it was challenging for her to get out of the house with Dalia to get to the shops. Patricia asked if I would mind if we went to the supermarket together instead of staying at home, and I agreed. I waited upstairs with Dalia while Patricia carried her wheelchair down the steep stairs from their first-floor apartment to the street and assembled it. Once we were all out of the house I helped Patricia get Dalia and the wheelchair into a taxi, and we went to the supermarket. There, Patricia got a yoghurt for Dalia, and we sat and had breakfast together in the cafeteria before shopping for ingredients. Patricia commented that in fact this was even better than staying at home in terms of being able to talk with me freely – Patricia and her family lived in the apartment above her in-laws, and her relationship with them was strained even before the separation from her husband. She had told me that her mother-in-law sometimes listened to her conversations from the from patio of her apartment and as a result she felt more comfortable talking about her personal life away from home. Thanks to the adaptability of the method, this outing became a rich source of ethnographic data, despite the change of plans.

Through initial analysis of data collected through participant observation (considering what was not said as well as what was spoken of), I developed questions for interviews and conversational prompts for the group discussions. I tended to use interviews to follow up on personal or sensitive topics that were particular to each individual or family, and group discussions based to gain a more nuanced understanding of shared experiences.

In-depth interviews

In-depth interviews offered an opportunity to collect data on more sensitive subjects and topics that did not arise organically during participant observation. I also followed up on themes that arose during participant observation in these interviews, probing for more detail. I had some standard questions that I drew on in most of the interviews, but generally I adapted the topic guide for each encounter based on the data I had already collected and previous conversations with the participant. I devised interview questions through iterative, continual preliminary analysis of the data I had collected.

I conducted audio recorded interviews with Rita, Patricia, Hilaria, Andrea, Julia, Catalina, and Beatriz. The majority took place at the participants homes at their request. This meant that the interviews took place in familiar surroundings, and also that other family members sometimes joined the interview part way through. Julia had very limited time as she had to take Stefano to therapy in the mornings, take the children home for lunch, then take her daughter to school and head home to cook dinner before picking her up again. She suggested meeting during her son's therapy session, so I interviewed her at a park near the therapy centre.

Photovoice and photo elicitation

I had planned to conduct participatory data collection and analysis using photovoice since the inception of this research project. Various aspects of my positionality informed this decision in the planning stage of my research. Given the socio-demographic distance between myself and the participants, I wanted to incorporate methods that would allow them to determine the direction of data collection, engage them as co-creators of knowledge, and serve their political agenda by culminating in an event aimed at reaching decision makers. I also understood photovoice to hold prestige as an established creative method in feminist research. The successful execution of a photovoice project had the potential to raise my profile as a researcher as well as benefiting the participants.

I made some observations during the early stages of data collection that I interpreted to be supportive of photovoice as a suitable method. Participants used

photographs as visual aids when telling me their stories, and this prompted reflection on past experiences. Participants had previous experience of working together to engage in activism through the foundation they had started to set up, and they wanted more opportunities for networking and peer support, which had been curtailed by the COVID-19 pandemic. However, as I became more familiar with the context and collected more observational data, I began to have doubts about the suitability of photovoice. Charmaz (2017, 2020) discusses doubt as "generative for critical inquiry" (2017, p. 38) and demonstrates how embracing doubt can deepen reflexivity and enable greater understanding of different perspectives. Following this, I decided to embrace this doubt and see where it might lead me upon further examination.

I observed that service providers attending to the children were required to take photographs of their activities and send them to managers as evidence. The recipients of such photographic evidence occupy similar positions to those who would likely form the audience for a photovoice exhibition. Thus, rather than shifting the balance of power in favour of participants and revealing systemic failings, asking participants to exhibit photographs to policy makers and service managers risked turning the onus back on to them to 'prove' that they were struggling. I also learned that privacy is a key concern for the participants, specifically in regard to photographs of their homes and children. It became clear that holding an exhibition of photographs was unlikely to align with participant values.

I also came to understand that existing demands on participants' time would likely make meaningful engagement in a photovoice project very difficult. Photovoice involves committing to a series of group meetings, and organising an exhibition is time consuming. It became clear that any group research activities needed to maximise opportunities for networking, peer support and collaboration, and minimise the burden of participating. I decided that I would not proceed with the photovoice project, as I had come to understand that it was not the right fit for the context.

I still saw value in holding group discussions and believed photographs to be a relevant resource to catalyse reflection and analysis of their circumstances. I came to understand that there is a distinction between existing photographs, which participants share with trusted acquaintances, family and friends to illustrate past events, and newly taken photographs, which serve as evidence in hierarchical structures.

Group discussions

I developed a plan to a series of group discussions using different approaches to prompt discussion and reflection among the participants, including photo elicitation using existing photographs. Each session was standalone so that participants could engage according to their availability. I redirected resources from purchasing cameras and printing costs to providing childcare, lunch, and refreshments to mitigate barriers to engagement. Participants travel expenses were also reimbursed. Rather than building towards impact in the form of an exhibition, the focus was on co-creating "impact-in-process" by providing a space for networking and peer support (Marzi, 2022). Discussing existing photographs was more in line with participants usual use of photographs and reduced the amount of work required to participate.

I held three group discussion meetings, in November 2022, January and February 2023. I advertised the meetings as taking place from 11:00-13:00, but most participants stayed long into the afternoon. The first hour was reserved for catching up and informal conversations as we waited for everyone to arrive. Once everyone was there I would welcome them and initiate a discussion using questions I had planned in advance. The participants were willing to respond to my questions and conversational prompts, but they also took the opportunity to raise topics of their own and ask each other questions. I was happy to let them direct the discussion and allowed my role to shift from discussion leader to facilitator. I prioritised bringing people into the conversation if they had not yet had a chance to speak and moving the conversation along if a topic ran dry.

The first meeting served as an opportunity for the participants to become re-acquainted with each other after a long period of limited contact due to the COVID-19 pandemic. I asked them to bring a photograph of their family to share with the group, as a prompt for discussion. However, only three families brought a photo, and as a result the discussion of the photos was limited. Nonetheless, the discussion went on for several hours, and participants increasingly led the direction of the conversation.

I did my best to keep the conversation going among the whole group, but parallel discussions emerged periodically. I occasionally had to step away from the discussion to coordinate the refreshments and lunch, and to help with the children. As a result, recording field notes during the group discussions was challenging. I tried to mitigate this by writing down a summary of each discussion after it ended. I had devised these sessions in part as a method of reciprocating for the participants' time and contributions, so I measured their success on the quality of the discussion among the participants, rather than the quality of my fieldnotes.

Data analysis

I selected constructivist grounded theory for my analysis. I take a critical approach to researching CZS, and I am concerned with uncovering power dynamics and hierarchies. Charmaz argues that the reflexive, emergent nature of this analysis method fosters the development of a critical stance towards the research topic and also towards ourselves as researchers (Charmaz, 2017). I am also interested in applying and developing theory through my analysis. With this in mind, CGT is a good fit for my research aims and approach.

I transcribed audio recordings and typed up my field notes as soon as possible after the data was collected. I kept all of the data in the language it was initially collected – my fieldnotes were a mix of Spanish and English, and all audio recordings were in Spanish. I hand coded existing data throughout the period of data collection in order to iteratively inform further data collection. This included noting emerging topics of discussion, developing questions for iterative data collection, and highlighting possible theoretical insights.

Once I had completed data collection and transcribed all audio-recorded data, I conducted in-depth analysis of the entire corpus as a whole. I refamiliarized myself with the data by re-reading the transcripts and notes, listening to excerpts from the audio recordings and referring back to my field diary. I then began to code the data, and went through an iterative process of coding, organising codes, writing memos, and engaging with theory. I used NVivo and Dedoose programs to conduct line by line coding of all the data. During and after the coding process I wrote memos that highlighted broader ideas related to the data and key theoretical links. I grouped some codes into categories based on their content. Throughout the analysis process I moved between reading theoretical papers and analysing the data. Based on the theory I was reading and my familiarity with the data and initial codes, I began to map out the main theoretical domains that I identified within the data. I developed these into chapter outlines. For each of these, I made mind maps of the codes and memos that related to the topic of that chapter. I analysed the data in the language it was originally collected, and translated excerpts and quotes into English for inclusion in this thesis.

Member checking

Member-checking and returning to the field to re-engage with existing participants can serve the needs of constructivist grounded theory, critical inquiry and decolonial methods (Madison, 2005; Charmaz, 2006; Munévar, Fernández Moreno and Gómez Castro, 2020). During the fieldwork period, initial analytic reflections on data are shared with participants to give them an opportunity to respond and offer corrections or clarifications (Charmaz, 2006; Vanner, 2015). Member checking increases the credibility of the research as well as improving construct validity (Lather, 1991; Birt et al., 2016). Through this approach, the meaning of the data is co-constructed through reflection and conversation between the participant and the researcher (Vanner, 2015; Birt et al., 2016). Dialogue with participants facilitates the development of meaningful interpretations of the data that are able to contribute to change for the participants (Madison, 2005; Birt et al., 2016; Chilisa, 2020b). True two-way dialogue with participants represents a tool for disrupting the

coloniality of knowledge production and research methods (Quijano Valencia, 2016, in Munévar et al., 2020, pp.50, my translation).

I engaged in member checking during data collection. The iterative process data collection and analysis created an opportunity to test my initial interpretations of the data. In informal conversations during participant observation and recorded in-depth interviews I asked questions based on my initial interpretations of the data, and participants responded, adding more detail or offering a slightly different interpretation. This helped to inform the development of further questions and topics of conversation, and shaped further rounds of analysis.

Challenges and limitations

I experienced a number of challenges in conducting this research, and the methodology has some limitations.

Sampling and recruitment

Participants belonged to an existing social group that had formed around their involvement in the VEZ cohort study. I was initially concerned that if all participants were recruited through a single gatekeeper (Rita) that some potential participants might be excluded if they were unknown to her. This was mitigated by the fact that I was able to recruit participants directly through the brigade visit, and that snowball sampling proceeded beyond the first set of referrals.

Recruitment to the cohort was based on robust epidemiological surveillance and follow up, so the vast majority of families raising children with CZS in Barranquilla and surrounds were invited to participate. However, those facing the most disadvantage may not have presented at a health facility or may have declined to participate if they felt that attending the cohort study visits would be too much of a burden on their time and resources. The participants in my research belonged to lower socio-economic strata, mostly strata 1 and 2, but participants in *pobreza extrema* (extreme poverty) may have been excluded based on the sampling approach used.

I was initially concerned that sampling from an existing study might make potential participants feel obligated to participate. While the cohort study staff are not the children's regular health care providers, they do provide care, referral and supplies once or twice per year, and maintain contact in between. The staff had become close with the families, particularly the mothers, and wherever possible they advocated for the families outside of their capacity as clinicians. I was grateful that the brigade welcomed me as an honorary member of their team during my stay but was also aware that this complicated my positionality and role in relation to the participants. In my explanation of the research, I emphasised the difference between the cohort study and my research. I explained that the doctors were helping me to identify potential participants, and that I had interviewed some of them, but that they were otherwise not involved in my research. Based on our interactions during sampling and recruitment and beyond, I did not pick up on any sense that participants felt obligated to participate based on my connection to la brigada. In contrast to their children's regular healthcare providers, with whom relationships could be strained and even combative at times, the mothers viewed the doctors of la brigada as allies, based on repeated positive engagements. I believe that my association with them lent me some credibility in the eyes of the participants during sampling and recruitment, before we had had the opportunity to establish an independent rapport.

Cancellations and delays

I faced a number of practical challenges during data collection. Rainy seasons in Colombia are regional and are shifting due to climate change. During my stay in 2022 there were two periods of rain that affected the Caribbean coast, one lasting from late April to June and another from late September to mid-November. The latter of these was more intense, with weeks at a time of torrential rain. Drainage in the city is unable to cope with these inundations, so the streets regularly flooded during the rainy months, becoming completely impassible. Research encounters and other events were frequently cancelled due to the weather during these periods, limiting my ability to collect data during these months.

Participants also had to cancel or postpone their participation in data collection when their children were unwell. Lola, Dalia and Máximo were all hospitalised during the time I spent in Colombia, and other children experienced more minor illnesses that were managed at home. By being flexible and maintaining regular contact with the participants I was able to re-initiate data collection after these periods of illness.

I travelled to Mexico in June 2022 to present at a conference and tested positive for COVID-19 shortly after arriving. I ended up staying in Mexico for twice as long as planned and was very unwell for around two weeks. After my isolation ended and I returned to Colombia, I experienced significant fatigue for the next two months, and regained my prior level of fitness very slowly. This made data collection challenging, as visiting participants usually involved spending over and hour on public transport to reach their home or the appointment, followed by a full day of data collection and the same journey back. The rhythm of data collection slowed during the period of my recovery.

Christmas and carnival are the main events of the year in Barranquilla. For Christmas, many of the participants either visited or hosted family for most of December. I was forewarned that data collection opportunities would be very limited during this period and opted to return to England for a visit. While the carnival technically only lasts for one long weekend in late February, there are events all across the city from January onwards, and the road closures for the main event begin two weeks in advance. This meant that data collection was more difficult during this time, mostly owing to congestion and road closures.

Personal safety

In the familiarisation phase of the research many contacts gave me advice about personal safety. They informed me about neighbourhoods that were experiencing higher levels of crime, including conflict between local gangs. Crime was a common topic of conversation, and there were a number of high-profile murders in the city during my stay. In addition to getting information through word of mouth, I stayed informed by following the local news. Based on these sources, I concluded

that the majority of violent crime in the city involved gang members engaged in extortion of local workers and business owners, or fighting to control territory[4]. This knowledge helped me to plan my activities and transport options to minimise the risk to my personal safety. I avoided travelling after dark and visiting neighbourhoods known to be areas of conflict between gangs.

I was warned about the dangers of using public transport, but also dissuaded from using taxis or walking. Without access to a private vehicle, the usefulness of this advice was limited. I followed recommendations about protecting my personal belongings while out in public, and remained vigilant while using public transport. I used the local bus network for the vast majority of journeys during the day, and taxis for long distances and after dark, and never experienced any difficulties.

Various contacts also warned me that as I stood out as a foreigner, I would be a target for pickpocketing and mugging. What was implied but mostly unsaid in these warnings was that I was also at risk of sexual harassment and violence. The fact that I stood out as both a foreigner and a woman travelling alone was very apparent to me, based on the stares, catcalling, and lewd gestures from men that I experienced in the street when I went out on my own. These were mostly brief encounters and while distressing, did not escalate beyond verbal harassment. Connor in particular repeatedly advised me that it was not safe for me to travel around the city on my own and suggested that he would accompany me to all research encounters. Based on the sensitive research topic, ethnographic methodology, importance of rapport, and ethical commitment to anonymity, this was not an acceptable option to me, and I declined. I discussed with each participant about whether it was safe for me to visit them at home. If they agreed that it was, they advised me on the safest mode of transport and time of day to reach

[4] In July 2022, three bus drivers were shot and killed while driving their routes in Barranquilla and Soledad (Semana.com, 2022). These murders were attributed to a gang who were attempting to intimidate and extort money from drivers in the city. As a result of these killings and the perceived failure of the authorities to safeguard these workers, bus drivers in the city held a series of strikes in July and August. Also in August 2022, three men were killed in a drive-by shooting in an incident that was believed to stem from a dispute between drug traffickers (Maestre, 2022). In September 2022, another drive-by shooting resulted in the deaths of six men outside of a billiards hall (El Tiempo, 2022). Again, this crime was attributed to disputes between gangs involved in drug-trafficking.

them. Participants were invested in my safety, asking me to share my location with them via WhatsApp when I was on my way and message them when I had made it safely home. They were more satisfied that I could travel around safely when I demonstrated my knowledge of the public transport system, which neighbourhoods I should avoid, and how to avoid pickpocketing.

I had anticipated that the greatest challenge of negotiating access to participants would be in demonstrating the objectives of the research and establishing trust and rapport. This proved to be more straightforward than I thought, and personal safety came to the forefront of my access challenges. The constant warnings that I was in danger combined with frequent street harassment took a mental toll, and there were times when I dreaded leaving the house. Several times I experienced harassment on my journey to a participant's house and arrived feeling upset and frustrated, which made it more difficult to focus on the research encounter. I sought emotional support through discussions with peers who were also experiencing challenges related to conducting fieldwork as solo female researchers. In terms of physical threats to my safety, I was involved in an attempted mugging in broad daylight while walking with Connor and another key informant – a community leader – around the corner from his home. I was unharmed and the key informant reassured me that such incidents were uncommon in his neighbourhood.

Reflexivity

Reflexivity is a key pillar of rigorous qualitative research underpinned by an interpretivist epistemology. The collection, interpretation and presentation of data is socially mediated and thus the social context of the research must be critically examined, including reflection on the researchers social position in relation to the topic and participants (Haynes, 2012; Manning, 2018). Reflexivity involves critical reflection on the overlapping dimensions of the researcher's positionality, motivation, affect, relationships in the context of the research (Davies, 2007; Reid et al., 2018; Dodgson, 2019; Lemos Dekker, 2019; Subramani, 2019).

My research sits at the intersection of anthropology and global health, two fields with deep histories of complicity in colonisation and neo-colonialism (Asch, 2015;

Packard, 2016). The role of meaningful, sustained reflexivity in the decolonisation of these fields has been emphasised in recent years (Asch, 2015; Calderon, 2016; Liwanag and Rhule, 2021; Sinha, 2021). Furthermore, as a feminist researcher I am committed to building relationships as the foundation of any research encounter, and must remain attentive to the imbalances of power that exist within these relationships (Vanner, 2015; Manning, 2018). As a result, developing a sustained and meaningful reflexive research practice has been an essential part of my growth and development as a doctoral researcher.

To me, reflexivity is an ongoing, dynamic process involving a constant movement between looking inward, looking outward, and taking action. Looking inward involves considering one's social position, motivations, interpretations, beliefs and feelings in relation to the research. Looking outward requires a systematic analysis of systems and structures, power dynamics, institutions and the relationships between them. Taking action involves planning the research and iteratively re-visiting plans, negotiating one's position in a given context, adjusting data collection methods, and re-visiting interpretations of data. This process begins at the inception of a project and continues throughout and beyond the completion of the research, and goes far beyond the static, two-dimensional positionality statements that have come to stand in for critical self-reflection in many cases (Robertson, 2002; Folkes, 2022). The orientation towards planning and action moves reflexivity beyond introspection and opens up the possibility that reflexive research can be transformative (Soedirgo and Glas, 2020). For me, engaging in critical dialogue with peers has been an effective way to mobilise and draw connections between introspection, analysis and action (Heller *et al.*, 2011; Liwanag and Rhule, 2021).

Collective reflexivity

From the first weeks of my PhD, I grappled with the prospect of significantly altering my data collection (and thus overall research project) as a result of the COVID-19 pandemic. Through informal discussions in online reading groups, journal clubs and postgraduate researcher coffee mornings, I saw that my peers were in the same boat. Based on this, I reached out to a small group of peers who

were also in the early stages of their doctoral research with plans to conduct qualitative data collection in the field of global health, with the idea of setting up a peer support group to discuss the challenges we were facing. What came out of our initial meeting was a shared desire for a space for reflexive discussions of our evolving research plans and the possible ethical and practical implications of the changes we were making. The pandemic was evolving all the time and thus our plans and positionalities were continually in flux. The pandemic represented a rupture in our carefully planned and imagined PhD trajectories and demanded that we critically assessed all aspects of our research (even those which remained relatively unchanged). We were using reflexive diaries and discussions with our supervisors to help us navigate and make sense of these changes, but we wanted a space for collaborative, accountable reflexive discussion with our peers. A group of us, five PhD students from the Institute for Global Health who began our doctoral studies in 2020 and 2021, began holding monthly meetings in mid-2021. The format of these meetings has been flexible, allowing us to respond to emerging challenges we have faced in planning, fieldwork, and analysis. For the first three months we mostly discussed how we were adapting our research plans in light of the COVID-19, and our shifting positionalities, motivations, and feelings in relation to the research.

Through these early discussions, we identified a shared interest in going back to the beginning and examining our motivations for carrying out our particular proposed research project. We felt that critically assessing what had brought us to our respective topics was an essential for an ongoing analysis of our evolving positionalities in relation to the topic, participants, and field. Through this process I determined that my primary motivation was to produce knowledge that was politically useful to the participants. I anticipated that this would mean producing outputs they could use to leverage access to more resources on behalf of themselves and their families. I also expected that other political objectives would become clear to me once I began collecting data. Through those first six months of discussion, I renewed my commitment to feminist research and the idea that I would transparently align myself with the most affected in relation to the topic. In doing so I hoped to learn about the political agenda of the participants and

understand the context they were operating in, in order to enable me to produce politically relevant research outputs.

Through our discussions over the first six months of meeting, we established a collective reflexive practice. Through repeated engagements we established our group meetings as a safe place to be vulnerable and ask ourselves and each other difficult questions. Maintaining the sense of a safe space while engaging in collaborative critical reflection that was entangled with our personal lives and feelings enabled us to keep the conversations generative rather than defensive. We focused on justifying and contextualising our ideas and decisions, rather than defending them. Critical questions from others about our research plans and thought processes helped us to move to a deeper level of reflection than we had previously achieved in our own individual practices of reflection. Facilitating and listening to the reflections of my peers informed my own thinking. The group discussion format and supportive environment fostered a sense of accountability: to keep asking difficult questions, to keep searching for answers, to maintain reflexive practice throughout and to enact research practices in line with our values. In addition to discussion, we shared literature that we had engaged with that had helped us to clarify our thinking or plan our research.

We moved constantly between looking inwards (analysing our own motivations, values, political stances that informed our approach to the research) and looking outwards (to the structural conditions that shaped our positionality, the research topic, and the field). Through this constant back and forth we established an orientation towards action, using our analysis to inform the selection of methods and strategies we could use to conduct ethical, rigorous, reflexive and perhaps even transformative research.

This space of collective reflexive practice increased my ability to cope with uncertainty in relation to the research. I knew that if the pandemic (or other circumstances) disrupted my research plans, I had a space available to talk through emerging ethical and practical challenges and arrive at a solution that was aligned with my epistemological stance and ethical principles. We continue to meet

regularly to engage in collective reflexivity as we proceed through different stages of our doctoral research and careers.

In terms of putting the reflections I developed through dialogue with my peers into action, I draw on Segato's (2015a) approach of *antropología por demanda* (anthropology on demand). This involves using ethnography to produce knowledge that answers the questions of the community at the centre of the research. I did not design this research in direct response to a call from the affected community, but I began with a broad research question and flexible methods which enabled me to develop an understanding of the participants' agenda and shape the direction of the research accordingly. I found that participants were keen to share their stories and increase awareness of the discrimination their children faced and the ongoing challenges they encountered in pursuit of health care, education and welfare. The doctors of *la brigada* were enthusiastic about my research and interested in incorporating my findings into their work in order to better serve the patients. I was invited to share my results with the team, which represented an opportunity for the participants experiences and views to shape future service provision and resource allocation. In addition to the demand for more resources, it became apparent to me over the course of the data collection that the participants wanted to re-establish a peer support group that they had previously set up. Their *fundación* had ceased operation during the first two years of the COVID-19 pandemic owing to the limited contact between the families in this period. Based on these observations, I decided to hold group discussions in addition to individual interviews. These meetings had an open and flexible format, and provided a space for the group to re-connect and discuss their plans to re-invigorate the *fundación*.

Positionality

A positionality statement is a necessary part of reflexive practice, but is often done poorly and used as a stand-in for continual engagement with reflexivity (Robertson, 2002). Different aspects of the researcher's social position become more or less salient at different points of the research process, and our positionalities are dynamic and shifting (Folkes, 2022). Thus, simply listing ones demographic characteristics, devoid of context and static, can obfuscate rather than clarifying

how the researcher is positioned in relation to the research topic and participants (Robertson, 2002). Through a continual process of collective and individual reflexivity, I have identified aspects of my social identity that shape my proximity to power and have thus informed my orientation towards the research topic, methodology, and overarching theories. I will discuss these here. Other aspects of my identity have become more salient at later stages of the research.

My earliest experiences of analysing structural inequalities, hierarchies and power dynamics stem from my experience of my gender as a cis woman. My experience of my gender and gender-based discrimination is inextricably related to being white, thin, cisgender, non-disabled and heterosexual – in relation to many other women living in the same context that I do, I occupy a position of relative privilege. My experiences of gendered inequalities have prompted me to examine the broader circumstances surrounding my individual experience, and I found feminism to be a resonant political stance to help me understand the world I was experiencing.

My family was supported by government benefits for most of my childhood. I received free school meals, and bursaries to support my secondary, further, and higher education. I have had a positive experience of education, which was enabled by the direct and indirect financial assistance I received, in combination with a stable living situation and supportive family, being neurotypical and non-disabled, white, and cisgender. Obtaining a post-graduate education has increased my future earning potential and positioned me culturally among the middle classes. Nonetheless, my PhD stipend is below the UK median income, and I supplement this with precarious employment in zero hours research and teaching roles. My experiences of limited financial resources and receipt of financial assistance led me to analyse the economic and political systems that advantage some at the expense of others. Through such an analysis, thinking both locally and globally, I arrived at an anti-capitalist political position. This has also prompted me to consider feminism from an intersectional perspective.

Discrimination and structural inequalities on the basis of race, ethnicity and migration status are all very much intertwined in a UK context. As a white woman with British citizenship, my commitment to anti-racism and an end to violent

borders is less informed by direct personal experiences than my engagements with feminism and anti-capitalism. However, an intersectional, anti-capitalist analysis of current events and discourse in the UK and on a world scale has illuminated the role that racism and anti-immigrant sentiment shape people's everyday experiences, access to resources, and opportunities for a dignified life.

These life experiences and facets of my social location have informed my approach to research broadly and to this research topic in particular. As I have discussed, my politics are informed by my lived and embodied experiences and an analysis of the world around me. As such, I believe that the personal is political, and I am invested in research that centres the stories, experiences, and views of the most affected by the issue at hand. Knowledge that centres that most marginalised can inform political interventions that respond to their needs and desires and promotes equity. Reflexive qualitative inquiry, and in particular critical ethnography and constructivist grounded theory, are well suited to the production of this kind of knowledge.

An analysis of the social, political and economic conditions of parenting have informed my decision to remain child free. My experiences in education have prompted me to consider how discrimination on the basis of disability and neurodivergence is inter-related with gender, race, and socio-economic status. My experiences of gendered discrimination and lens of trans-national, intersectional feminism made me particularly attuned to the gender-exploitative narratives that were employed in the public health discourse around the Zika virus epidemic in the Americas. All of this has informed my interest in this research topic, my critical evaluation of the existing literature, and the research methodology I have used.

Developing a political stance orientated towards understanding and resisting structural inequalities led me to question where and how these inequalities originated. Decolonial theory has been instrumental in my understanding of the contemporary political economy and my analysis of structural inequalities. In the following chapter I will discuss my theoretical approach to this research.

Chapter 3: Theoretical perspectives

Introduction

This thesis is underpinned by decolonial theory, primarily of the Latin American coloniality/ modernity school. In this chapter, I will first discuss how these theories inform my approach to knowledge production. I will then explain how I conceptualise each of the main themes of this thesis – gender, disability, and care – from a decolonial perspective. Finally, I advance an argument that paying attention to practices and relations of care for and with cognitively disabled people can illuminate the tensions between the coloniality of being and the assertion of personhood. I explore this argument further in the following chapter.

Colonisation and coloniality in Colombia

The modern nation state of Colombia takes its name from Cristobal Colon, the navigator who led the first Spanish fleet to arrive in the Americas in 1492. This voyage precipitated the first wave of European colonisation of the Americas, led by Spain and Portugal (Tombs, 2002). The express purpose of this 'exploration' was to establish trade routes and conquer territory in order to enrich the European nations (Galeano, 1971; Tombs, 2002). The Spanish initially conquered a number of islands in the Caribbean before turning their attention to the territories that make up present-day Mexico, Central America and Peru (Tombs, 2002). From positions in Panama, Peru and the Caribbean, Spanish expeditions entered the territory of present-day Colombia (Safford and Palacios, 2002a). The diverse terrain and climate of this region presented a challenge to the colonising forces; their progress was slow and their control of the territory uneven and fragmented (Safford and Palacios, 2002b). Nevertheless, by the mid 1500's the Spanish had established a number of cities, brought the Indigenous populations under their control, and implemented an *encomienda* (forced labour) system similar to that which had already been established in the Caribbean colonies (Safford and Palacios, 2002b). Indigenous people were forced to labour in gold mines and agriculture, and in the Caribbean region of Colombia, the Spanish enslaved and sold Indigenous people to the rulers

of the established island colonies (Safford and Palacios, 2002a, 2002b). Exhausting, dangerous work and the spread of new diseases from Europe decimated the Indigenous population (Safford and Palacios, 2002b). As the availability of Indigenous labour declined, increasing numbers of enslaved West African people were brought into the country through the port of Cartagena (Safford and Palacios, 2002b; Barragan, 2021). As European, Indigenous and African peoples increasingly came in to contact, the Spanish implemented a hierarchical system of racial classification, represented in Figure 6 (Wade, 2010).

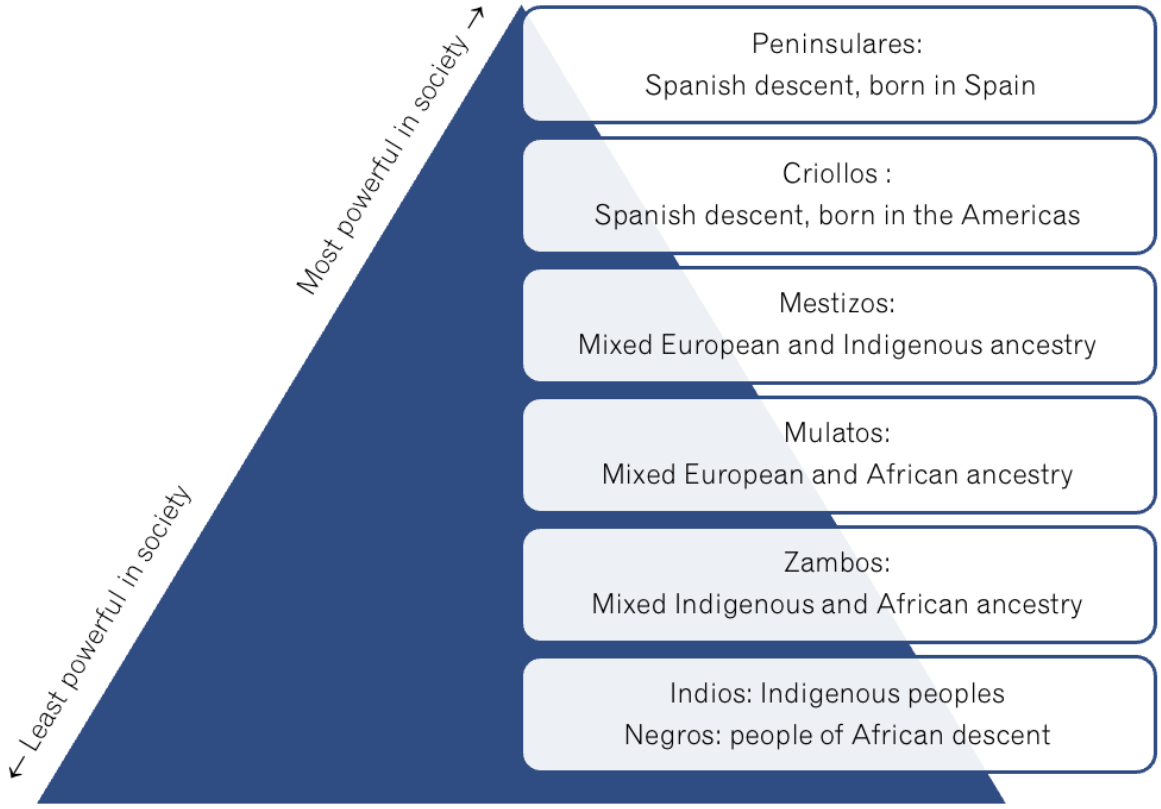

Figure 6: Racial caste system imposed by the Spanish in Latin America in the colonial period. Adapted from (Chavez-Duenas, Adames and Organista, 2014; Wade, Scorer and Aguiló, 2019)

European goods entered the market and the Indigenous population had little choice but to engage in trade in order to obtain gold to pay tribute to their new rulers, so the material culture of the colonisers and local population began to blend (Safford and Palacios, 2002b). Prior to colonisation, the population had been widely

dispersed and the land was occupied by families or small communities (Safford and Palacios, 2002b). The Spanish forcibly concentrated the population into new towns organised around churches, which served two purposes (Safford and Palacios, 2002b). The first was to bring the population under tighter control and into closer proximity to the church, in line with the Christianising mission of the conquest (Safford and Palacios, 2002b). The second was to free up land for the Spanish to claim as their own, granting them ever greater control of the territory (Safford and Palacios, 2002b). The Spanish conquest brought about fundamental changes to the social, political, economic, demographic, and geographical order of the region.

The Spanish fought a number of costly wars against both England and France in the 1700's and, as a result, sought to increase revenue through increased exploitation of the colonies (Safford and Palacios, 2002c). In order to do so, they attempted to raise taxes and placed *Peninsular* officials into important colonial administrative positions (Safford and Palacios, 2002c). Both measures were met with dissatisfaction and dissent from the *Criollo* elite, sowing the seeds for an eventual republican rebellion against the Spanish crown (Safford and Palacios, 2002c). The fight for Colombia's independence from Spain was led by the white, male, *Criollo* elite, who sought direct control over country (Wright, Rolston and Ní Aoláin, 2023). As Colombia transitioned to an independent state, colonial, patriarchal and Catholic social structures were influenced by conservative politics and notions of citizenship and human rights (Luna, 2003). These developments did not override the prior colonial discourse but incorporated it, and as a result, "the entire contemporary Colombian state is built on the foundations of Spanish colonialism" (Luna, 2003; Wright, Rolston and Ní Aoláin, 2023).

The coloniality of power and knowledge

The coloniality of power is a central theory within the coloniality/ modernity school of decolonial thought (Mendoza, 2016). Quijano (2007) finds that classification and subordination according to a racial hierarchy originated in the period of colonisation, beginning as a social hierarchy and then being naturalised through supposed biological differences. Labour and exploitation were organised along

racial lines, and colonial labour relations and extraction established Europe as the centre of the global capitalist system (Quijano, 2000a). The two inseparable axes of racialisation and capitalist exploitation that have outlived the physical act of territorial colonisation established what Quijano refers to as the 'coloniality of power' (Quijano, 2000a). This has become the framework for modernity – capitalism as the dominant global political economic model, and a global social hierarchy based on racial othering (Maldonado-Torres, 2007).

European hegemony was not restricted to control of territories or the global economy, and has outlived the period of territorial colonisation (Alonso Bejarano et al., 2019). The coloniality of power shaped the development of dominant worldview and system of knowledge production born out of "the fusing of the experiences of colonialism and coloniality with the necessities of capitalism" (Lugones, 2007; Quijano, 2007, 2000b, pp.343). Serving the needs of capitalism involves the measurement and classification of both people and nature in order to maintain social hierarchies (Quijano, 2000b). This system privileges Western methods of inquiry and ways of knowing, establishes Westerners as those capable of knowing and engaging in reason and rational thinking, while racialised peoples are denigrated as irrational and lacking the capacity to know (Quijano, 2007). Within this hierarchy, white Europeans are defined as subjects, capable of reason, rationality and an ability to project these in order to gain control over others (Quijano, 2007; Vallega, 2014). Racialised others, meanwhile, "can [only] be 'objects' of knowledge or/ and of domination practices" (Quijano, 2007, p. 174). Taken together this constitutes the coloniality of knowledge (Quijano, 2007).

The coloniality of being

The very humanity of peoples globally is implicated in the coloniality of power, knowledge and gender (Maldonado-Torres, 2007). Quijano's explanation of the vertical hierarchy between peoples based on racial classification and organisation of labour (the coloniality of power) can be understood as an ordering of society that assigns lesser humanity to racialised (colonised and enslaved) peoples (Maldonado-Torres, 2007). Within the coloniality of being, humanity itself is

necessarily exclusive, and defined by evolving notions of the essence of humanity. As Mendoza (2016) puts it, "those conquered through violence were condemned to a zone of non-Being, stripped of humanity, rights, and self-determination" (p. 113).

The coloniality of being refers to the ways that coloniality has shaped what we deemed to be human and what we deem to be the essential characteristics or attributes of humanity. Wynter (2003) finds that in the medieval period humans and humanness were defined in relation to God: humans were God's subjects. What defined somebody as having humanity or not having humanity was determined by sin, particularly sexual transgressions (Wynter, 2003). One could "fall to the level of the beasts by giving in to his passions", in other words, be stripped of his humanity on the basis of his sin (Wynter, 2003, pp. 276–277). Europeans considered the populations they sought to colonise to be "man made degenerate by sin" (Wynter, 2003, p. 302), and Spanish colonists debated the question of whether Indigenous peoples in the Americas had souls, and were thus of equal humanity to themselves, or not (Tombs, 2002; Maldonado-Torres, 2007). Stripping these peoples of their humanity through this religious demarcation provided a justification for the violent subjugation of these peoples who they believed would otherwise "not adopt by themselves the superior Christian religion and culture" (Maldonado-Torres, 2007, p. 246). Indeed, the conquest of the Americas was sanctioned by Pope Alexander VI on the basis of spreading the Catholic faith (Tombs, 2002).

The question of whether Indigenous people were fully human was eventually settled in 1537, but by that time, relationships between the colonisers, Indigenous populations and the land were already deeply entrenched and the ruling had little effect on the treatment and conditions of the Indigenous population (Tombs, 2002; Maldonado-Torres, 2007). Indigenous peoples were forced to labour for Spanish estates, mining precious metals or working the land, ostensibly in exchange for religious tutelage as well as a daily wage and decent conditions (Tombs, 2002). In practice, they were forced into slavery in all but name, and Indigenous peoples were ravaged by harsh conditions, cruel punishment and novel diseases brought by the Europeans (Tombs, 2002; Quijano, 2007).

Mignolo (2003) refers to the colonisation of the Americas as the "darker side of the Renaissance", and shows that the ideas that developed in Europe during this period were informed by the ongoing conquest of territory and peoples in the Americas. Indeed, "the Spanish and Portuguese pioneered the European ideology in which the world was theirs to conquer and rule for the social and religious good of other peoples" (Tombs, 2002, p. 8). With the dawn of the Enlightenment era and ascendence of the scientific method, rationality and intellect were cemented as the essential traits of the human (Vallega, 2014). Within the established dualistic world view, the existence of the rational Being (the subject, human, man) is constructed against "the idea of the absence of Being in others" (Maldonado-Torres, 2007, pp. 252–253). Indigenous and racialised peoples were excluded from the category of human, and the white, European man was established as the one Man (human) to the exclusion of all else (Maldonado-Torres, 2007). That such hierarchies are perpetuated to this day demonstrates the fact that coloniality (the continuing dominance of the worldview and social order established through colonisation) is constitutive of modernity (Quijano, 2007). I will explore the relationship between gender, disability, humanity and coloniality in the following sections.

Gender

Gender is a central theme of this thesis. I understand gender to be a relational, bio-social structure produced through overlapping power relationships (Barbieri, 1993). A relational approach emphasises the 'dynamic and situational' nature of gender and conceptualises gender as 'multi-dimensional' structure which is constituted by a set of power relationships at different levels – global and local, institutional and interpersonal, political and economic (Connell, 2012; Springer, Hankivsky and Bates, 2012). Black feminist scholarship proposes that hierarchies of power based on gender, race, social class, and sexuality intersect to produce distinct forms of oppression (beyond a simple 'additive' effect) (Hill Collins and Bilge, 2016). Crenshaw (1991) refers to this phenomenon as 'intersectionality'.

Patriarchy refers to a specific gender order characterised by domination and control over people and nature which is established and maintained through

control over institutions and the direct exercise of force (Johnson, 2014; Christ, 2016). Decolonial feminists have elaborated on the origin and nature of this domination on a global scale.

The coloniality of gender

Lugones (2007, 2010, 2016) draws together the coloniality of power, the coloniality of being, and intersectional theories of gender to develop the coloniality of gender. She finds that in addition to domination based on a new racial hierarchy, colonisation "imposed a new gender system" that ordered relations among the colonizers and the Indigenous peoples as well as between them (Lugones, 2007, p. 187, 2016). Lugones posits that prior to colonisation, hierarchies of gender did not exist in Indigenous communities (Lugones, 2007). Other decolonial feminist theorists have critiqued this suggestion, arguing instead that prior to colonisation, Latin American society was characterised by "low-intensity communal patriarchy"(Segato, 2015b) or "ancestral patriarchy" (Paredes, 2009) in which social and linguistic categories differentiated people on the basis of gender, and prestige was unevenly assigned to men and women, but that these categories were more fluid and flexible than in the Western gender order. As Tamale (2020) puts it, pre-colonial gender dualism was "more pluralistic, elastic and accommodating"(p. 62). Rather than imposing an entirely new gender order, Segato (2015b) finds that European colonisation transformed the gender system of the colonies within the colonial (racialised) matrix of power. Paredes (2009) refers to the process by which "ancestral patriarchy" fused with European patriarchy as *entronque patriarcal* (interlocking patriarchy). Based on their own gender order in which the public sphere was considered the domain of men, Europeans sought out men to act as intermediaries to their communities (Segato, 2015b). In doing so, the importance placed upon Indigenous men's role within their communities was amplified (Segato, 2015b). At the same time, Indigenous men faced violence and subjugation in the public sphere (Segato, 2015b). The division between the public and private spheres was deepened through colonial relations, and through these processes, the gender order was transformed (Segato, 2015b). The "interlocking" of ancestral and

colonial European patriarchy with the colonial racial hierarchy, produced a "planetary system of patriarchal domination" (Paredes Carvajal, 2024, p. 156).

Lugones, Segato, and other decolonial feminists share the view that the establishment of a new rigid, binary, hierarchical gender order (that Segato refers to as "high-intensity colonial-modern patriarchy") was essential to ordering relations between and among the colonisers and colonised peoples (Segato, 2015b; Lugones, 2016; Mendoza, 2016). They thus advance upon Quijano's coloniality of power by showing that the construction of gender and race are co-constitutive of one another – gender is racialised and race is gendered – and social hierarchies are organised according to hierarchical matrices of race with gender (Lugones, 2016). Lugones (2010) states that "beginning with the colonization of the Americas and the Caribbean, a hierarchical, dichotomous distinction between human and non-human was imposed on the colonized in the service of Western man" (Lugones, 2010). Thus racial and gender hierarchies are constitutive of the coloniality of being; the category of race was conceived to exclude racialised peoples from the category of full humanity (2010, p. 743). Gender is "bifurcated" by race: the racialised gender order excludes racialised and colonised women from humanity, so that rather than having true gender, they are seen in terms of their sexuality (Lugones, 2010; Mendoza, 2016, p. 117). This was used as further justification for the subjugation of Indigenous ways of being, as European norms of gender and sexuality were enforced upon them in order to 'civilise' them, through the institutions of heterosexual monogamy, marriage, and the nuclear family (Lugones, 2007; Segato, 2015b; Nahwilet Meissner and Whyte, 2017). European women are subjugated to European men but retain their humanity within this system through their position in the racial order. Under this racialised gender order, Indigenous and enslaved peoples were construed as part of 'nature' rather than culture, lacking rational thought, and available for exploitation in service of patriarchal capitalism (Mies, 1998a; Lugones, 2010; Bauhardt, 2018). From a decolonial feminist perspective, patriarchy can thus be understood as a specific gender order characterised by the domination of those deemed to be non-human or less-human on the basis of their position in the racialised gender hierarchy.

The new racialised gender social order was entrenched through the negotiation of treaties, the enactment of laws, imposition of institutions such as marriage and the nuclear family, and violent policing and disciplining of bodies and behaviours (Lugones, 2007; Segato, 2015b; Nahwilet Meissner and Whyte, 2017). Male domination of women and patriarchal domination over the family became embedded in the laws and institutions of the independent republics that followed decolonisation in Latin America (Franceschet, Piscopo and Thomas, 2016). The subjugation of women and racialised peoples is perpetuated to this day through law, policy, institutions and norms, constituting the coloniality of gender (Lugones, 2007).

The gendered division of labour

The imposition of the colonial gender order involved the categorisation of peoples according to a rigid binary based on biological sexual characteristics, including reproductive capacity, and the organisation of society around heterosexual nuclear family units (Segato, 2015b). Within this biologically determined gender binary, responsibility for sustaining the biological and social lives of the family, including waged workers, was assigned to women based on the idea that "women's household and child-care work are seen as an extension of their physiology" (Mies, 1998b, p. 45). Mies (1998a) coined the term 'housewifization' to refer to this process of confining women to the domestic sphere ad making their labour invisible. Marxist-feminists developed social reproduction theory to explain how women's role in the privatised, domestic sphere was integrated into and essential for capitalist exploitation of men's waged labour in the public sphere (Valiavicharska, 2020).

Women of colour and feminists from the Global South have critiqued the notion of 'housewifization', highlighting that it pre-supposes a particular type of woman (white, middle class, European), a certain type of home (heterosexual, nuclear family), and a certain type of labour (productive or reproductive) (Hall, 2016). Black feminists draw attention to the fact that since the beginning of the transatlantic slave trade, Black women in the West have worked outside the home, whether under duress or out of necessity (Jones, 1949; Davis, 1981). Indigenous feminists

show that in Indigenous communities, the categories of productive, reproductive and non-productive (subsistence) labour can be highly fluid (Hall, 2016).

Notwithstanding their involvement in waged or subsistence labour, within the patriarchal institution of the family, women do the majority of the unpaid reproductive labour – reproducing the productive labour force, raising the next generation, and caring for the old, sick, and impaired (Erevelles, 1996).The gendered division of labour is not confined to the nuclear family unit, but is reproduced on a global scale through relationships of migration, labour, and trade, constituting the political economy of gender (Mies, 1998c; Bakker, 2007). The 'integration' of women into the productive economy has frequently involved using the female labour force to fill precarious, low-paid, menial roles, and has not relieved them of their disproportionate workload in the reproductive sphere (Rathgeber, 1990).

Reproducing coloniality

The global politics of reproduction are deeply colonial and distinctly gendered. Control over population demography has been utilised as a mechanism to control territory and people for centuries. Under the established gendered division of labour, women are responsible for the reproduction of populations, both biologically and socially, and have thus historically been the targets of population control efforts (Kuumba, 1993). In settler colonies, the colonisers wished to replace the native population and claim the land, and thus demographic control was essential to the colonising mission (Conceicao, 2020). As Quijano (2007) has shown, the establishment of a hierarchical system of racial classification was central to early European colonisation. This racial hierarchy was upheld and reinforced through population control. In terms of biological reproduction, this meant discouraging or actively preventing Indigenous people from becoming pregnant while encouraging white settlers to have more children. In Australia, Indigenous women were subjected to forced sterilisation while incentives were given to white women to reproduce and grow the settler population (Soldatic, 2015). In terms of social reproduction, Indigenous children were removed from their families and placed in boarding schools or with white adoptive families (Wesseling and Reimer,

2020). The aim of these policies was to assimilate Indigenous children into whiteness and advance the genocide of Indigenous peoples through the destruction of their culture and kinship structures (Wesseling and Reimer, 2020). In the context of colonial plantations, the reproduction of enslaved people in the Americas was controlled according to the price of import compared to the cost of feeding and housing enslaved people (Schwartz, 2010).

In the Enlightenment era, the explicit focus on population control for colonial gain was replaced by a concern for social issues such as poverty, undernutrition, the spread of disease and the destruction of the environment (Whelan, 1991). This did not spell the end for the colonial racial hierarchy, rather the coloniality of power was perpetuated through the fusion of philosophical and scientific advances in the Enlightenment era. The principles of freedom and equality were central to the revolutionary and liberation movements that established modern nation states in Europe and the Americas (Safford and Palacios, 2002c; Conceicao, 2020). Adopting these principles without disturbing the status quo of settler colonialism and slavery required a retrenchment of the racial hierarchy, narrowing the definition of 'human' in order to deny the human rights of racialised peoples (Conceicao, 2020). This was achieved through the application of the new (pseudo)scientific ideas and methods that were being simultaneously developed in the period. The publication of Darwin's theory of evolution revolutionised scientific understandings of heritability and the health of populations across generations (Conceicao, 2020). Darwin's notions of fitness and competition were adopted as explanations for social inequalities and, together with other pseudoscientific interventions such as phrenology, laid the foundations for scientific racism and the eugenics movement (Dennis, 1995). Eugenicists argued that the human race could be bettered through selective breeding among 'fitter' groups, and suppression of reproduction by the 'unfit' (Dennis, 1995). The betterment of the human population was tied to ideas of progress and modernisation of the nation, and accepted definitions of fitness followed established hierarchies of race, class, ability, intellect and health (Rembis, 2018). The popularisation of eugenics resulted in the forced sterilisation of poor, sick, disabled, mentally ill and racialised people (Conceicao, 2020; McConnell and Phelan, 2022).

Eugenics and 'racial purity' were central to the ideology of Nazi Germany, and it was only after the atrocities of the Holocaust were uncovered that the movement was finally denounced by the international community (Conceicao, 2020). With the establishment of supranational organisations and widespread decolonisation following the Second World War, 'international development' became a key foreign policy focus of countries in the Global North (Grimes, 1998). Countries in the imperial core attributed the 'underdevelopment' of colonised and newly independent states to high birth rates and population growth (Grimes, 1998). Domestically, social issues were attributed to higher birth rates among poor and racialised populations (Grimes, 1998). As a result, governments began to invest in a range of population control interventions directed at their own populations, or overseas in the form of 'development aid' (Grimes, 1998). Many programs aimed to increased access to contraception and provide information about family planning (De Silva and Tenreyro, 2017). However, coercive and deceptive tactics were also widespread. This included giving racialised women long acting contraceptives without proper informed consent or facilities for removal, and subjecting them to forced or coerced sterilisations and abortions (Oliveira, 2021; Vergès, 2021; Vasquez Del Aguila, 2022; Boydell, Smith, and Global LARC Collaborative, 2023).

The systems of "stratified reproduction" (Colen, 1995) established along racial lines in the colonial era are reproduced through the continued targeting of women's reproductive capacity. Women's bodies are constructed as a threat to or tool in service of colonisation and coloniality based on their racialised gender position. Their reproductive autonomy is constrained, denying them full equality even within 'modern' liberal democracies.

Reproductive justice

The reproductive justice framework was initially developed by Black feminists in the USA, as a critique of racialised population control and an alternative to the mainstream white feminist movement's demands for reproductive choice and freedom (Ross and Solinger, 2017a). Whereas the reproductive rights movement centred on access to abortion and the 'right to choose' when and whether to have a child, reproductive justice recognises that for many women, the right to have and

raise their children had also been denied (Ross, 2017). The reproductive justice framework recognises the right bodily autonomy, encompassing the right to not have a child, to have a child, and to raise children in safe and healthy environments (Ross and Solinger, 2017b). The framework is based on an intersectional understanding of gender, and understands limitations on bodily autonomy to be both a cause and a consequence of gender inequality (Ross, 2017).

The relationship between reproductive justice and disability has been explored primarily in relation to the rights of disabled people to have and raise children, and the right not to give birth to a child with a congenital impairment. In particular, research has focused on the reproductive autonomy of disabled people, and reproductive decision making when an actual or possible congenital impairment is detected during pregnancy.

Disabled people, particularly those with cognitive impairments or mental illness, are subjected to reproductive injustices underpinned by ableist discrimination. McConnell and Phelan (2022) refer to the "devolution of eugenic practices" to describe the reproductive control and coercion that disabled people are subjected to in the present day. Ableist discourses of deficit and dependence shape the view that disabled people are unfit to raise children, and thus, that pregnancy is a risk to be avoided (McConnell and Phelan, 2022; Pacheco et al., 2024). Disabled women with cognitive impairments in particular are targets of reproductive control, often through deception or coercion by family, partners, medical providers and the state (McConnell and Phelan, 2022; Pacheco et al., 2024). Intellectually disabled women are frequently pressured in to accepting long-acting contraception or sterilisation procedures, or given them without informed consent (McConnell and Phelan, 2022; Pacheco et al., 2024). They are routinely denied excluded from comprehensive sex and relationships education and denied access to sexual and reproductive health services (McConnell and Phelan, 2022; Pacheco et al., 2024). Family members, support staff and healthcare providers intervene to prevent individuals with cognitive disabilities from entering into intimate relationships, and exert undue control over these relationships when they do form (McConnell and Phelan, 2022). Disability discrimination also pervades child welfare policy, and cognitively

disabled parents are subjected to disproportionate scrutiny, intervention, and ultimately the removal of children from their care (McConnell and Phelan, 2022).

The possible births of disabled children have frequently been raised in debates over reproductive rights, with the reproductive autonomy of women placed in opposition to the rights of disabled people. Those arguing in for increased access to pre-natal testing and abortion have framed these arguments in terms of offering pregnant people the opportunity to make an informed decision about if and how to proceed with their pregnancy, and ensuring that they are able to terminate their pregnancy if they choose to do so (Bagenstos, 2019; Ginsburg and Rapp, 2023).

Others have argued that promoting access to abortions specifically in cases where a congenital disability is detected perpetuates the practices of eugenic by attempting to prevent the births of disabled people (Jarman, 2015). Feminist disability studies scholars have adopted a reproductive justice perspective to try and resolve the apparent tension between reproductive rights and disability rights. They highlight the limitations of 'individual choice' as it is put forth in mainstream movements for reproductive rights, and draw attention to the broad structural factors that constrain both reproductive freedoms and disability rights.

Reproductive decision making following a prenatal test cannot be removed from the context of disability discrimination, limited support, neoliberal health and welfare systems that place limitations on the lives of disabled people (Dietz, 2022; Ginsburg and Rapp, 2023). In medical settings, patients often have difficulty interpreting test results and distinguishing between elevated risk and diagnosis (Ginsburg and Rapp, 2023). Nonetheless, termination of the pregnancy is often framed as the 'responsible' choice in light of any 'positive' result (Jarman, 2015; Ginsburg and Rapp, 2023). Individuals occupying marginalised social positions are likely to face the greatest difficulties raising a disabled child in an ableist society and also face the greatest restrictions on their reproductive autonomy (Jarman, 2015). Finally, the possibility of using test results to begin preparing for the birth of a disabled child is seldom raised (Ginsburg and Rapp, 2023). From this perspective, it is clear that the promise of 'informed choice' is seldom realised, and that women's reproductive

options may in fact be increasingly restrained by the very interventions that are supposed to offer greater choice (Jarman, 2015).

Disability

A number of models of disability have been developed over time that guide how disability is defined and understood, and thus the way that people with disabilities are treated in society. The models of disability that currently dominate Western institutions are the biomedical model and the social model. The biomedical model frames disability as an individual deficit that is classified in relation to the "normal", and as something to be overcome through medical rehabilitation (Llewellyn and Hogan, 2000; Smart, 2009). In contrast, the social model finds that the deficiency is with a society that discriminates against and excludes people with mental or physical impairments, and thus that disability itself is socially constructed (Llewellyn and Hogan, 2000).

The movement for disability rights that emerged in the second half of the 20th century in the UK and USA led to a number of important legal changes that advanced the rights of people with disabilities (Hinton, 2021). The movement also brought about the development of the academic field of Disability Studies, and the mainstreaming of the social model of disability (Hinton, 2021). The WHO International Classification of Functioning, Disability and Health (ICF) and UN Convention on the Rights of People with Disabilities (CRPD) acknowledge the role of the environment and social context in the construction of disability, and call for an end to discrimination, enabling participation and independence, and inclusion for people with disabilities (Jette, Martin and Field, 2006; Equality and Human Rights Commission, 2020). Activist demands for recognition of the role that social construction plays in disability have brought about changes to law and policy that aim to reduce exclusion and facilitate participation for people with disabilities. Through these processes, the social model of disability has achieved mainstream recognition and acceptance.

Critical approaches

As the social model of disability has become mainstream, a number of important critiques of the model have been put forward. Impairment as a distinct concept from disability is a central contribution of the social model of disability (Shakespeare and Watson, 2001). Critics argue that this distinction has led to the marginalisation of embodied experiences of the impairment itself, which have come to be treated as secondary to social barriers (Barnes, 2009; Silvers, 2010). Critics also argue that an examination of the social production of impairment has been overlooked, since impairment has become naturalised within the social model (Kafer, 2013a; Hall, 2019). In response to these critiques, Kafer (2013a) draws on feminist and queer theory to propose a 'political/ relational' model that positions both impairment and disability as constructed through social relations, and attends to these embodied phenomena within their political context. This model enables an examination of the impact of societal ableism on all people, not just those with impairments, and offers a more nuanced consideration of the role of biomedicine (Kafer, 2013a). A number of authors have further intervened to illuminate the social mediation of disabling processes. Berlant puts forth that work under capitalism is a 'practice of slow death', referring to the ways that fulfilling the demands of neoliberal capitalism requires the "physical wearing out of a population and the deterioration of people in that population" (Berlant, 2007, p. 754). Puar (2017a) expands on Berlant and others to develop her arguments about the biopolitics of debility as a method of population control. She uses the concept of debility to expose the violence of the everyday under neoliberal capitalism (Puar, 2017a). Debility as a concept offers a way of understanding embodied experiences of neoliberal exploitation and neglect (Puar, 2017a). Méndez de la Brena applies Puar's conceptualisation of debility to her analysis of women's experiences of chronic pain in Spain (Méndez de la Brena, 2022). Williamson, Engel and Fietz (2023) draw on Puar's notion of debility in their theorisation of dis/abling care, which will be discussed further in Chapter 6. Beyond this, the concept has received limited attention from Latin American disability studies scholars.

The removal of social barriers to promote independence for people with impairments is central to the social model. However, a feminist critique reveals that the social model centres particular subjective experiences of independence and participation as they might exist for a white, adult male subject living with a physical disability or otherwise limited mobility (Valim, 2020). Such a framework marginalises the experiences of women, children, and those with complex and cognitive disabilities, for whom the type of independence that the social model prioritises may not be possible or desirable (Valim, 2020). Placing such value on the pursuit of independence not only forecloses consideration of what social justice might look like when dependence is an inevitability, but in so doing, also devalues relationships of care (Kittay, 2011). Efforts to promote 'independence' all too often fall back on an individualist, capitalist logic that assigns value to individuals based on their productivity (Ferrari, 2020; Parra, 2020). Desires to 'normalise' disabled bodies, driven by a biomedical, deficiency-based understanding of disability, have been replaced by more subtle modes of control and the need for conformity (Parra, 2020).

Evident in the critique that the social model privileges white male experiences is the fact that early Global North Disability Studies (sometimes termed white Disability Studies) were overwhelmingly white and lacked an analysis of race in relation to the construction and experience of disability (Hinton, 2021). Black Disability Studies has a long history in its own right and more recently has also put forward important critiques of mainstream white Disability Studies (Bell, 2006; Miles, Nishida and Forber-Pratt, 2017; Hinton, 2021). Black Feminist Disability Studies have been particularly instrumental in the development of intersectional analyses that examine race, gender and disability as inter-related and co-constitutive systems of oppression that have their roots in colonisation and slavery (Bailey and Mobley, 2019; Hinton, 2021).

Considerations of the political economy of gender, sexuality, and disability in the context of a neoliberal global economic system by queer theorists has resulted in the development of Crip theory (McRuer, 2006; Bennett, 2007). Crip theorists offer robust critiques of normative expectations of gender expression, sexuality, and

bodily form and function (Sandahl, 2003; McRuer, 2006). Crip theory has been particularly influential in offering a critique of normative notions of time in relation to disability (Kafer, 2013b). The concept of "crip time", which asks us to consider how experiences of disability alter the subject's experience of time, has been widely adopted (Kafer, 2013c). Kafer (2013d) also invites us to consider the idea of the future as it relates to disability, which is so often neglected or denied.

The development of the social model of disability represents an important shift away from the deficit centred medical understandings of disability and towards social justice. The shift from medical to social understandings of disability by supranational organisations was a step in the right direction, but uncritical reliance on the social model risks reproducing some of the very same dynamics it was intended to subvert (Silvers, 2010) . Furthermore, international conventions rely on the assumption that rights on paper create paradigm shifts that in turn transform systems of oppression and advance equality, which cannot be taken for granted in societies marked by severe inequality and political instability (Yarza de los Ríos et al., 2020).

Coloniality of disability

The Eurocentric models developed by white Disability Studies are limited in their ability to provide a full and rich understanding of constructions and experiences of disability in post-colonial settings (Grech, 2015; Ferrari, 2020; Parra, 2020; Yarza de los Ríos, Mercedes Sosa and Pérez Ramírez, 2020a). Despite this, they are often treated as universal and uncritically applied to contexts other than those in which they were developed (Ferrari, 2020; Yarza de los Ríos, Mercedes Sosa and Pérez Ramírez, 2020b). In order to resist these universalising moves, Global South scholars have developed distinct areas of critical disability studies that more fully attend to colonialism and coloniality.

Decolonial disability studies advance upon the social model of disability by situating the social construction of disability within the colonial matrix of power and domination. Scholars from Indigenous groups, the Global South, and their diasporas have highlighted that considerations of colonisation and coloniality are

missing from mainstream models of disability (Grech and Soldatic, 2016). This is a glaring omission for two interrelated reasons. First, colonisation was a major cause of impairment, through armed conflict, subjugation and punishment, disease, environmental destruction, malnourishment and poverty (Meekosha, 2008; Soldatic and Grech, 2014; Grech, 2015; Parra, 2020). Second, the imposition of the category of disability as it was understood in the colonising countries (as a negative trait based in personal deficit) was part of the process of dehumanisation and subjugation of Indigenous and enslaved populations (Ineese-Nash, 2020).

The coloniality of disability can be understood as a facet of the coloniality of being. The shift towards rationality and reason as the essence of humanity, in the Renaissance period, laid the foundation for the exclusion of people with certain impairments from the category of human, based on their perceived lack of capacity to engage in rational thought or reason. Goodley (2023) finds that certain groups of disabled people, particularly those with intellectual disabilities, can be counted among those who "inhabit the underside of 'the category of man-as human'" since "able-bodied-and-mindedness is framed as a marker of human worth" (2023, pp. 169–170). Per Maldonado-Torres (2007), reason and intellect only have meaning when cast against the lack thereof in another. The embedding of these hierarchies into institutions and policies is the foundation of broad societal ableism (Dirth and Adams, 2019).

Latin American Critical Disability Studies

Latin American scholars working in the field of Disability Studies have developed a distinct branch of Critical Disability Studies. They explicitly acknowledge that the development of the social model of disability opened up discussions of the social construction of disability (Rojas Campos, 2020; Yarza de los Ríos et al., 2020). Despite the critique that mainstream models of disability are Eurocentric, the aim is not to disparage or discount existing contributions, but to enter into a "critical dialogue" that creates space for other experiences and interpretations (Ferrari, 2020; Parra, 2020; Yarza de los Ríos, Mercedes Sosa and Pérez Ramírez, 2020a, p. 10). This includes drawing on other critical traditions, Global South Disability Studies and alternate epistemologies (Munévar, Fernández Moreno and Gómez

Castro, 2020). Indeed, there is a hope that such dialogues will create space "to speak and think in terms of Disabilities Studies, in plural, or better yet Critical Studies in Disabilities" (Yarza de los Ríos et al., 2020, p. 37).

What distinguishes Latin American Critical Disability Studies from other Global South Disability Studies is the use of Latin American decolonial and feminist perspectives on power, race, gender and knowledge. Scholars working in this area highlight the fact that decolonial perspectives on power, race and gender fail to adequately consider disability as an organising principle in the social hierarchization that was essential to the colonial project and is constitutive of and perpetuates the coloniality of power (Morán and Tiseyra, 2019; Parra, 2020). Through the dominance of models of disability developed by white Disability Studies, and the lack of consideration of disability in decolonial thought, understandings of disability have come to be "dominated by hegemonic matrices of thought from the Global North" and thus unable to account for the historically situated experiences of people with disabilities in Latin America (Danel, 2020; Ferrari, 2020; Parra, 2020, p. 63). In order to address these omissions, Latin American Critical Disability Studies brings together Latin American decolonial theory, global south feminisms, and contributions from critical disability studies. This facilitates an elaboration on the coloniality of (dis)ability and furthers our understanding of processes of subjugation of certain bodies, and subjugation based on bodily difference (Morán and Tiseyra, 2019; Ferrari, 2020; Munévar, Fernández Moreno and Gómez Castro, 2020; Parra, 2020). Drawing on decolonial theory helps to situate the social production and social construction of disability within the specific historical context with regards to early colonisation by European countries and the proceeding 500 years of exploitation.

Care

The subject of care has received considerable attention in the fields of anthropology, gender studies and feminist theory, and disability studies (Buch, 2015; Thelen, 2015; Fietz and Mello, 2018). As such, care has a multiplicity of co-existing meanings (Fietz and Mello, 2018). It can be understood as a task or set of

practices to be performed, and a related attitude, feeling, or set of 'virtues' that responds to a need or set of needs in another (Buch, 2015; Fietz and Mello, 2018). For Marxist feminists, care can be understood as the practices required to sustain and reproduce life (Bakker, 2007; Mezzadri, Newman and Stevano, 2022). As discussed in a prior section, the division of responsibilities for these practices is highly gendered. Buch (2015) reviews a number of important anthropological perspectives on care and concludes that the diverse perspectives share a concern for "the ways that care is involved with the social constitution of personhood" (pp. 280–281). In her own review of anthropological perspectives on care, Thelen (2015) aims to move beyond care in the realm of kinship. She finds that care is a set of socially embedded processes that constitute (and dissolve) significant relationships (Thelen, 2015). Synthesising Buch and Thelen, we find that care is a process that sustains life, and that investing time and effort in stabilising and sustaining life is a way of producing relationships and asserting personhood.

All people have needs that must be met in order to sustain life, and thus the support needs associated with impairment can be understood as a part of natural human variation (Mello and Nuernberg, 2012a). Vilela Garcia (2020) adopts this perspective in her argument that all people engage in processes, on behalf of themselves or others, to promote and sustain life, and thus that the support needs of children with CZS should not be understood as 'abnormal', but simply responding to a different set of 'vital norms' (Vilela Garcia, 2020).

Thinking about care through a lens of disability also opens up space for the possibility that care can be a harm as well as a social good (Thelen, 2015; Fietz and Mello, 2018; Nadasen, 2021). Thelen's (2015) conceptualisation of care as a process that can constitute, stabilise and dissolve social relationships is particularly instructive here. Care may stabilise social relations in such a way that upholds or prolongs a harmful status quo (e.g. the social construction of disabled people as dependent and passive) or dissolve significant relationships (obscuring the legitimacy of individuals' and communities' demands of the state for the sustenance of their lives) (Bakker, 2007; Thelen, 2015; Fietz and Mello, 2018). A consideration of the potential social harms associated with care as it is embedded

in larger social structures lays the foundation for an examination of the role that care plays in the lives of disabled people.

Care and assistance for disabled people

Owing to their impairments and the barriers they encounter in the environment, disabled people may require additional assistance to sustain their life and health. Such assistance may be paid or unpaid, provided by professionals, relatives or friends. Paid assistance may be purchased directly by the disabled individual (using private funds or cash benefits), or by an agency or facility on behalf of the individual (Kelly, 2011). The dynamics of the global care assistance workforce is not the focus of this work, but it must be noted that in the majority of countries this work is undervalued and low paid, and the workforce is highly gendered, racialised and reliant on migrant labour (WHO, 2024).

Unpaid assistance is typically provided by close family members, either in conjunction with or in place of paid assistance (Grassman, Whitaker and Larsson, 2009). In many low- and middle-income countries, the limited availability of assistance services means that unpaid, family care is the primary form of assistance available to disabled people, and this is especially true for disabled children (Hunt and Watermeyer, 2017). As Grech (2023) puts it, for many disabled people living in poverty in the Global South, "the family effectively becomes the only source of social protection" (p. 117). As discussed, the gendered division of labour means that in practice, unpaid family care is provided primarily by women and girls (WHO, 2024).

Problematising care

Those aligned with the rights based approach distinguish assistance, which can afford greater independence and autonomy, from care, which can be premised on dependency and limitations on choice and freedom (Pino-Morán, Rodríguez-Garrido and Burrone, 2023). The disability rights movement in the Global North has highlighted that 'care for' disabled people has historically been delivered through medicalising, paternalistic institutions and thus represents a source of marginalisation and oppression of disabled people (Kelly, 2011; McLaughlin, 2020).

In family and community settings, assistance that is provided without "choice and control" on the part of the recipient can replicate these oppressive structures and produce relationships of dependency (Björnsdóttir, Stefánsdóttir and Stefánsdóttir, 2015; McLaughlin, 2020, p. 399). Caregivers have control over intimate aspects of the life of the person they care for, which can create a power imbalance and undermine the dignity of the disabled person (Kittay, 2011; Keyes, Webber and Beveridge, 2015). This can create the conditions for abuse and neglect, and even when caregivers have good intentions, can nonetheless constrain the disabled person's autonomy and participation. Independent Living advocates argue for forms of assistance that maximise opportunities for choice and agency on behalf of the disabled person (Mladenov, 2012; McLaughlin, 2020). The preferred model of enabling assistance is through centrally funded, directly purchased personal assistance which affords the disabled person the choice of what kind and how much assistance they receive, how and from whom (Mladenov, 2012).

It has been argued that this perspective is particular to adults with physical impairments and is not necessarily inclusive of the experiences of individuals with cognitive impairments (Kelly, 2011). In addition, notions of care and dependence are necessarily mediated by age in the case of disabled children and adolescents, (McLaughlin, 2020). For disabled children and young people, care provided by family may be seen as part of everyday family life and not particular to their impairment, in contrast to assistance from devices or paid professionals (McLaughlin, 2020). However, parents and family caregivers can be over-protective towards disabled children and young people, resulting in limitations on their autonomy (Mill, Mayes and McConnell, 2010; McLaughlin, 2020).

It has also been noted that independence as it was conceived of by the disability rights movement has been appropriated by neoliberal governments as a justification to reduce social welfare programs (Toorn, 2021). Various authors have moved to reclaim care and dependence both from their historical association with oppressive institutions and from their recent appropriation by neoliberal actors. They critique the notion that dependence on another is necessarily disempowering, and point out that in some cases, the nature of an individual's impairment

precludes complete independence (Kittay, 2011; Keyes, Webber and Beveridge, 2015). In light of this, they have developed conceptualisations of care grounded in care ethics, interdependence and relational autonomy (Kittay, 2011; Keyes, Webber and Beveridge, 2015).

Care in the absence of assistance in Latin America

In Latin America, the commitment to independence and the promise of autonomy for disabled people outlined in the UN CPRD has not been fully realised. Policy and legislation concerning care and assistance is developing slowly and unevenly, and the voices of disabled people and their allies are largely missing from decision making processes (Batthyány, 2015; Vásquez Encalada and Pereira, 2023). Disabled people in the region experience high levels of unmet need for support with the activities of daily life (Vásquez Encalada and Pereira, 2023). Unpaid family support is the main source of assistance available, and this is primarily provided by women (Batthyány, 2015; Vásquez Encalada and Pereira, 2023). Data on the availability and uptake of personal assistance are scarce, but the finding that family members provide the majority of support suggests that access to such services is limited (Vásquez Encalada and Pereira, 2023). Two recent reviews have revealed a dearth of research in this area in Latin America, and the Global South more broadly (Pino-Morán, Rodríguez-Garrido and Burrone, 2023; Riobóo-Lois et al., 2024). As a result, Latin American interventions into the debate around care and assistance are limited.

Disability, care, and being

Dirth and Adams (2019) show that coloniality imposes prescriptive 'ways of being' and affords individuals their humanity on the basis of their capacity to conform. The normative way of being is that which serves the needs of the (neo)colonial project, and ways of being that fall outside of this norm are perceived as 'deviant' and lacking in humanity (Dirth and Adams, 2019). Reading this together with Maldonado-Torres, I understand that within the social order defined by coloniality, one's humanity is determined depending on an individual's capacity to conform to the normative way of being (human). The modern human subject is defined by a

capacity for rational thought and reason, encapsulated in the statement, "I think therefore I am" (Maldonado-Torres, 2007). This conceptualisation of the relationship between capacity and being results in the dehumanisation of people whose cognitive or corporeal form or function falls outside the narrow normative range.

What makes an impairment disabling depends on the capacities required by the social structure in a given context. 'Hierarchies of impairment' have been identified, in which impairments that are understood to produce the greatest functional limitations within a given context are consistently placed low on the hierarchy of impairment by both disabled and non-disabled people (Deal, 2003). Cognitive impairments are frequently ranked as more functionally limiting, and other disabled people have been observed to distance themselves, consciously or otherwise, from those with cognitive impairments (Harris *et al.*, 2023). The impulse to distance oneself from disability, or from a disability that is perceived to confer greater functional limitation than one's own, can be understood as an attempt to claim humanity by distancing oneself from "the group that is still made to occupy the nadir" of the less-than-human (Wynter, 2003, p. 261). As we see from the established hierarchies of race and gender, the denial of humanity is inherently relational – the humanity of one group is constituted by the dehumanisation of the 'other'.

Others have argued that care is implicated in the assertion of the personhood of the individual being cared for (Buch, 2015; Williamson, 2024). I wish to connect these arguments to the coloniality of being and the dehumanisation of individuals with cognitive disabilities. Personhood refers to how one is perceived and valued by others, and being seen as less than human constitutes a devaluation of the individual and thus diminishes their personhood (Wickenden, 2010). Williamson (2024) has shown that investing in providing enabling care for children with CZS represents an assertion of their personhood. Connecting this directly to the coloniality of being, I put forth that caring for a child with a complex, cognitive impairment represents and investment in sustaining their non-normative lifeway, asserting the value of such a way of being (human). While care has historically devalued and made invisible through its association with women, this argument

demonstrates that it is worth paying close attention to care if we are interested in understanding how the humanity of individuals with cognitive impairments is negotiated in the context of societal ableism. This argument will be explored further in Chapter 4.

Concluding remarks

The intertwined concepts of gender, disability and care are the central themes of this thesis. In this chapter, I have discussed the theoretical perspectives that inform my understanding of each of these concepts. This understanding lays the foundation for the empirical findings that make up the rest of this thesis.

Gender is a system of interrelated power hierarchies that orders relationships between people. The present gender order of 'high-intensity colonial-modern patriarchy' (Segato, 2015b), in which women are subjugated to men, was established during the colonisation of the Americas, and the coloniality of gender is perpetuated through systems and institutions. The establishment of a gendered division of labour was essential to the colonial project and capitalist exploitation, and similarly pervades to this day. The naturalisation of the caregiving role to women, regardless of their involvement in waged or subsistence labour, is perpetuated through institutions like the family, religion and education.

Disability is an embodied social phenomenon that is produced through the interaction between 'bodyminds' (Schalk, 2018) and their environments. There is a wide spectrum of cognitive and corporeal form and function among human beings, and the social, political and physical environments in which we live are similarly diverse. Cognitive or corporal differences can be disabling when they inhibit the individual from conforming to the normative 'way of being' (Dirth and Adams, 2019) within a given context. From a decolonial perspective we see that the normative corporeal and cognitive way of being was established during colonisation, and thus disability (it's 'other') is a colonial construct too. Societal ableism is based on the embedding of the normative way of being in systems and structures, and the punishment of deviance from the established norm.

Care is both a feeling and set of practices that respond to the needs of another. As such it is relational, and practices of care (re)constitute important social relationships. All people have needs that must be met in order to sustain life, and thus care is an essential part of social reproduction. Owing to the interaction between their impairments and the barriers they encounter in their environment, disabled people may require more external input in order to sustain their lives. The disability rights movement includes a demand that disabled people should be empowered to the greatest extent possible to manage their own care and assistance independently. In many contexts, the promise of independent living has not been realised, and family members are the primary source of care and assistance to disabled people. In practice, given the established division of labour, women provide the majority of unpaid care for disabled people.

An analysis grounded in the coloniality of being reveals that patriarchy and ableism share a foundation in the denial of humanity to one group as constitutive of the humanity of another. I take the dehumanisation of individuals with cognitive impairments as the starting point to examine the gendered care work involved in sustaining their lives. In the following chapters, I will explore how mother-carers of children with CZS interact with ableist systems from their own gendered, classed and racialised social positions.

PART II: CARE

Chapter 4: Care and the politicisation of motherhood

Introduction

In this chapter I will discuss mother-carers' experiences of caring for a child with CZS. An examination of gendered care in the context of disability can illuminate the push and pull between the coloniality of being and the assertion of personhood for disabled children living in precarious circumstances in the Global South. This relationship of care is central to the entire thesis, so in addition to making a specific contribution, this chapter forms the empirical foundation for the rest of the thesis. I will first talk about what an analysis of care for disabled children can illuminate in terms of the institution of motherhood, the gendered division of labour, and disability policy. I will then discuss how such dynamics of care shape experiences of motherhood. The intersection of societal ableism with the patriarchal institution of motherhood shapes the experiences of individual mothers raising disabled children. Care is highly concentrated with the mothers, and they often feel that they are the only ones who are capable of caring for the child. Mothers report that it took them significant time and effort to learn to care for a child with CZS, but that it would be possible for others to learn. Existing research on mother-carers frequently relies on individualising conceptualisations of motherhood and the notion of a 'good mother' (Knight, 2013). Placing such emphasis on the mother risks obscuring the structural barriers that mother-carers and their children face (Knight, 2013). Such narratives of motherhood are not universal, however, and I have identified a political stance towards the maternal role among my interlocuters. I bring together Runswick-Cole and Ryan's notion of 'unmothering disabled children' with theorisations of political motherhood from Latin America in order to explore how structural violence against their children causes a rupture between the imagined maternal role and the reality, forcing them to reconceptualise their role from a political perspective. Children with CZS experience structural violence in the form of ableism, familism and the neo-liberal health system that together limit the exercise of their right to health and wellbeing, education, and a dignified life. In the context of structural violence and the highly gendered division of reproductive labour, rather than accepting the obligation to be 'good mothers', mother-carers

make it their mission to ensure that their child receives 'good care', both from themselves and from other caregivers. Mother-carers assert their child's personhood through their commitment to ensuring they are well cared for. By making an outward demand for 'good care' provided by the state and other caregivers, they assert their child's personhood in the public sphere.

Gender, disability and care in Colombia

Gawel (2023) defines care as "the social, material, and emotional weaving that sustains life and connects us to others" (p. 3). As this definition makes clear, care is both a feeling and a set of tasks (Watson *et al.*, 2004). The tasks involved in caring are those that sustain life by meeting the needs of oneself or another. All people have needs that must be met in order to sustain life, however children and adults with disabilities may require direct care provision from another person for longer periods than those without impairments or long-term conditions (Mello and Nuernberg, 2012b; Harvey, 2015; Gawel, 2023). It can also take longer for caregivers to develop confidence in their ability to look after a disabled child than a non-disabled one (Van Wyk and Leech, 2016). Both the feelings and practices associated with care are intensified for parents raising disabled children, and thus care in this context merits particular attention.

Familism

Family provide the majority of care for disabled people in Colombia (Correa-Montoya and Castro-Martínez, 2016). Welfare systems that delegate responsibility for care to the private sphere of the family are referred to as 'familist' (Gesser, Zirbel and Luiz, 2022). Such neo-liberal welfare policies aim "to shift all responsibility for survival from the state to the individual and the family" (Safa, 2002, p. 44). In the context of patriarchy and the gendered division of labour, familist welfare policies ensure that in practice, women do the majority of the care (Gesser, Zirbel and Luiz, 2022). As discussed in Chapter 3, both the gendered division of labour and the framing of disability as a deficit have their roots in the colonial period (Gesser, Zirbel and Luiz, 2022). They are perpetuated through institutions, including the nuclear family and marriage, and systems, such as welfare and education, which

impose normative ways of being and punish deviance (Dirth and Adams, 2019). As such, familist welfare policy perpetuates the denial of disabled citizenship and reinforces the coloniality of being.

Familism is not limited to direct aspects of personal care, inclusion and participation; carers are also made responsible for ensuring that rights of people with disabilities are protected (Acero and Duarte, 2019). The rights of people with disabilities are encoded in Colombian law and its ratification of the CRPD. However, the state derelicts its duty to protect and promote the rights of people with disabilities (Correa-Montoya and Castro-Martínez, 2016). A familist approach to disability rights is encoded in Colombian disability policies which position family carers as key agents in guaranteeing the rights of people with disabilities, without providing them with support or assistance to do so (Bacca, Sabogal and Arrivillaga, 2020). An analysis grounded in the coloniality of being makes clear that human rights are insufficient for overcoming coloniality, as the very meaning of humanity is a colonial construction (Maldonado-Torres, 2017). Disabled people's humanity and citizenship is denied, and the responsibility for upholding their rights and protecting their wellbeing is passed to the family. Familist policies completely ignore the gendered aspect of care, though it is widely known that women perform the majority of care work (Bacca, Sabogal and Arrivillaga, 2020). As with direct care work, the (female) family carer's role in the pursuit of rights is rendered invisible through neo-liberal, familist policy (Bacca, Sabogal and Arrivillaga, 2020). An analysis based in feminist political economy reveals the importance of care work for reproducing the population and sustaining the productive labour force, and also shows how care has been marginalised, undervalued and rendered invisible through its association with the private sphere and with women (Mies, 1998a; Rodríguez Enríquez, 2012; Gesser, Zirbel and Luiz, 2022). Under such neoliberal, familist regimes, women's capacity to provide care is assumed to be available and 'elastic', such that in times of crisis it can be called upon to pick up the slack and take pressure off of the state (Tanyag, 2017). This was clearly illustrated across diverse contexts during the first year of the COVID-19 pandemic, when women's unpaid care work increased disproportionately to that of men (Craig, 2020; Lokot and Bhatia, 2020; Pasqualini et al., 2022).

While care is undervalued in economic terms, it is assigned great symbolic and moral value. The symbolic and moral value of care, mediation of relationships between individuals and the state, and gendered division of labour produce and reinforce the social institution of motherhood.

The meaning of motherhood

Motherhood is both an experience and a social institution (Robertson, 2014). In the academic literature, a discussion of the structural factors shaping the experience of motherhood all too often missing. Research on the experience of motherhood when raising a disabled child has often focused on the (negative) emotions associated with receiving a diagnosis of impairment for an unborn or newborn child (Kearney and Griffin, 2001). Others have highlighted the positive aspects of raising children with disabilities (Beighton and Wills, 2019). Within research that examines the emotions associated with the experience of mothering a disabled child, gendered roles and expectations are usually acknowledged, but the role of patriarchy and ableism in shaping the emotional experience of motherhood are under-explored (Harvey, 2015). Much of the research on the emotional experience of motherhood implicitly adopts a medicalised, deficit-based understanding of disability and seldom discusses societal ableism (Kearney and Griffin, 2001; Harvey, 2015). More recent contributions have brought attention to the role of stigma and discrimination in shaping the experience of motherhood for mothers of disabled children (Ryan and Runswick-Cole, 2008; Robertson, 2014; Green, Darling and Wilbers, 2016). However, attention to ableism has not been universally adopted; a 2016 review of literature on the transition to motherhood for mothers of disabled children did not mention or discuss ableism or discrimination (Van Wyk and Leech, 2016). The way that the interaction between gendered oppression and disability discrimination shapes experiences of motherhood remains under-explored. On the other hand, an analysis of the social institution of motherhood is illuminating in terms of the social construction of gender and disability, and how these intersect.

Motherhood is “a powerful social institution that shapes the lives of subjects in modern society” that is produced through the entanglement of gender with care

(Mack, 2018, p. 2). The purpose of this institution is the reproduction of the current and next generation, and as such, engagement in care work is highly implicated in the social construction of motherhood (Mack, 2018). Within the family unit, this means that women are made primarily responsible for raising children, feeding the family and caring for the home. Beyond the family unit, 'good motherhood' is also defined in relation to the state. Through her analysis of the *Oportunidades* conditional cash transfer program in Mexico, Smith-Oka (2013) has shown that 'good motherhood' means performing the role of intermediary between population and the state (collecting benefits, attending heath facilities etc). This is deeply entangled with racialised attempts to control the population by controlling the reproduction of certain groups (Smith-Oka, 2013).

A number of authors have identified dominant themes in the social construction of motherhood, which I believe demonstrate how the social institution of motherhood mediates the interaction between the family unit and the state. 'Intensive mothering' refers to the individualisation of child rearing responsibility to mothers, which is typically coupled with the expectation of complete dedication to the role (Mack, 2018). The tasks associated with this role include mediating the relationship between children and the state through ensuring their attendance at school and child health appointments. The role of mediation is formalised and gendered by cash transfer programs such as the one analysed by Smith-Oka (2013), in which economic resources are transferred specifically to the mother provided that the relevant conditions are met. 'Masochistic motherhood' is defined by self-sacrifice and self-denial, and the dutiful completion of, sometimes painful and tiring, domestic labour (Knight, 2013; Mack, 2018). There is a moral value assigned to such self-sacrifice in service of supporting productive labour and reproducing the next generation of offspring. 'Unattainable motherhood' is the implicit result of the unrealistic expectations for mothers that restrict their ability to succeed in the domestic or public sphere, and can produce feelings of guilt and shame based on their perceived inability to live up to these expectations (Van Wyk and Leech, 2016; Mack, 2018). 'Total motherhood' requires women to maximise efficiency and minimise risk in order to raise the next generation to be "effective citizens and subjects" (Mack, 2018). This reinforces neoliberal notions of self-sufficiency and

suggests that the mother's life should be organised around the child (Van Wyk and Leech, 2016; Mack, 2018). The 'ideal mother' often reflects a patriarchal imagination of a white, upper- middle class mother in a heterosexual nuclear family. As such, while the *experience* of mothering can be empowering, the *institution* of motherhood within the hetero-patriarchal nuclear family perpetuates gender inequality (Mack, 2018).

In the Colombian context, the institution of motherhood is shaped by conservative, Catholic ideals and gender norms. Within the racialised gender order, Catholic ideals of honour and virtue shape constructions of women's roles in society and the family in Colombia and Latin America more broadly (Luna, 2003; Wright, Rolston and Ní Aoláin, 2023). Motherhood is a core feature of feminine identity and women's role in society (Luna, 2003; Albor Chadid, Reales Vega and Valero Díaz, 2018). Suffering and self-sacrifice for others are internalised as part of womanhood and intimately linked to reproductive labour, as women are expected to sacrifice their own wellbeing and aspirations in order to care for others (Albor Chadid, Reales Vega and Valero Díaz, 2018; Gesser, Zirbel and Luiz, 2022).

Motherhood and disability

In many ways, raising a disabled child intensifies the requirement that women adhere to established social ideals associated with motherhood. For mothers raising disabled children, self-sacrifice, resilience, and adaptability are central to the construction of the 'good mother' (Knight, 2013; Van Wyk and Leech, 2016). Disabled children require specific types of care, often over longer durations than non-disabled children. Narratives of 'good' motherhood and the imperative to live up to a maternal ideal while raising a disabled child have been identified among mother-carers in Colombia. Sacrificing one's own ambitions and giving up work or study in order to dedicate oneself to full time care appears to be a key aspect of being a 'good mother' in this context (Díaz Alzate and Ramírez Taborda, 2022). Mothers whose circumstances dictate that they must continue working to make ends meet feel like 'bad mothers' (Ramírez-Bustamante and Camelo-Urrego, 2022).

Within the coloniality of being, the very notion of citizenship can be exclusionary of disabled people, and thus the very existence of a disabled child represents a failure to reproduce "effective citizens" (Mack, 2018; Brunet, 2020). The 'unattainability' of motherhood is therefore intensified, and there is an imperative to engage in 'total motherhood' by employing technologies and techniques in order to 'overcome' the child's impairment (Brunet, 2020). The mother's ability to meet the child's needs is also implicated in the value attributed to motherhood (Hernández Galeano and Puerta Gil, 2014). Ableist society is characterised by barriers to the full enjoyment of rights by disabled people, and thus the role of meeting a disabled child's needs is made more difficult. Resilience and stoicism are typical attributes of a 'good mother' to a disabled child, and this is reflected in the idea that a good mother does not complain even when she is deprived of support (Díaz Alzate and Ramírez Taborda, 2022). Attributing moral value to individual resilience and stoicism obscures the responsibility of the state to redress the neglect of disabled people and their caregivers. The internalisation of such ideas of what makes a 'good' and 'bad' mother cause feelings of guilt and shame when they inevitably cannot be realised (Díaz Alzate and Ramírez Taborda, 2022; Ramírez-Bustamante and Camelo-Urrego, 2022).

The figure of the 'good mother' reflects a highly individualised view of care for people with disabilities, and illuminates the way that the gendered responsibilities usually placed on mothers are amplified when the person they care for has high support needs (Knight, 2013). Such a focus on family dynamics reinforces patriarchal and ableist norms of care, and draws attention away from the political structures and social systems that shape the experiences of people with disabilities and their carers (Knight, 2013).

Caring for children with CZS

Raising children involves diverse forms of reproductive labour regardless of any impairment or illness they may have (Mauldin, 2017). Compared to caring for a child without a disability, care of children with CZS is more "intensive" (Williamson, Engel and Fietz, 2023, p. 468). The intensity does not decline over time (either over

the course of each day as the mother is constantly vigilant even when the child is sleeping, or over months and years, as the children are unlikely to become more independent over time) (Robertson, 2015; Pinheiro, 2018). In the absence of more robust state support, the intensity of the care required intensifies how care is gendered, resulting in care work being especially concentrated with the mother. This intensified caring role is reflected in the terms that the participants in this research use to refer to themselves collectively – 'madres-cuidadoras' or 'mother-carers'. Focusing on the care of children with CZS thus allows an opportunity to analyse the political economy of care and the implications of the coloniality of being for disabled personhood. I will do so here through an analysis of three mothers' stories: Julia, Andrea and Patricia.

"Estoy sola"

Julia, Patricia, and Andrea each independently shared versions of the same sentiment when explaining how responsibility for childcare was divided in their households: "*estoy sola*" – I am alone. In this simple statement they demonstrate their lived experience of the gendered division of labour and familist welfare policy.

Julia is in her late twenties, she lives with her husband and two children, a ten-year-old daughter named Alicia, and a six-year-old son called Stefano. When I first met Julia, she told me that she first came to Barranquilla from a smaller city several hours away to look for work. She had to leave her job when she had her daughter Ariana. She wanted to go back to work but it was difficult with a young child to care for. She got pregnant with her son when her daughter was 3 years old. Julia was infected with Zika at 3 months gestation, and Stefano was diagnosed with CZS. Julia has cared for him full time since he was born. I asked, "so now your work is the house and the children?" and she said "yes, I do all of that".

I had noticed in previous discussions that the notion of reproductive labour was work of (at least) equivalent value to waged work resonated with mothers. This influenced the phrasing of my question. When I interviewed Julia, I revisited the topic of the household division of labour.

Ros: Okay, we already talked about the family a little, and I would like to ask about how you divide the household responsibilities between you. You told me your husband works at a furniture company, right?

Julia: Yes.

Ros: And [you told me that] you care for the children?

Julia: Yes.

Ros: Okay, could you talk a bit more about who is responsible for which tasks in the household?

Julia: Well, that's simple in that sense, the father works and brings in the money. That's it. I do everything round the house. At the weekends he would help me to clean the fans, or organise the patio, or whatever else we need to do, but that's not every weekend. It's every so often, maybe once a month.

[…]

Ros: Okay, maybe I already know the answers to the next questions but, who does the cooking?

Julia: Oh, me. No, he wouldn't be in the kitchen doing that.

Ros: And who cleans the house?

Julia: Yes, I do that.

The gendered division of labour is taken for granted in Julia's explanation of how she and her husband share household responsibilities. Care is clearly situated within the family. Julia lives far from her maternal family, though she remains close with them and visits when she can. She told me, "I don't have the support of my family, that is to say, *estoy sola* (I'm on my own). I have my husband's family, but everyone has their own obligations to attend to". The assumption inherent in her statement is that the family has ultimate responsibility for the care of disabled children, and that in particular mothers are charged with this role. Self-sacrifice as an inherent part of motherhood and care work is also evident in the fact that Julia came to Barranquilla looking for work, and wanted to continue working after she

had children, but gave up on her plans first to care for her young daughter and then to look after Stefano.

Andrea was infected with Zika in the first week of her pregnancy with her only son, Maurice. She had a traumatic delivery, and Maurice went without oxygen for several minutes while trapped in the birth canal. As a result, Maurice was diagnosed with cerebral palsy in addition to CZS shortly after his birth. He has seizures, does not have control of his bladder or bowel, and has a feeding tube. Due to the complexity of his impairment, Andrea sought nursing support to help her care for Maurice when he was five years old. She had to take legal action (a tutela) against her health insurer to force them to provide this service. Six months before our interview, the insurer finally granted them the service of a nurse[5], Isabela, who comes to the house to care for Maurice for 12 hours every day. Andrea lives with her husband Jorge, Maurice's father, who works outside the home. They live in a two-story building that is divided into three apartments. Jorge's parents live on the ground floor, and his brother's family lives next door. Having the assistance of a nurse has enabled Andrea to study. The course mostly fits around her daily routines with Maurice, but sometimes she has classes in the evening and can't get home before Isabela leaves at 7pm. Andrea told me that she could rely on her husband or in-laws to watch Maurice if she couldn't get home before Isabela was due to leave. She told me: "The nurse leaves at 7pm. Since I'm studying in the evening, my sister-in-law or brother-in-law – Maurice's uncle and aunt – they'll look after him until I get home around 9pm, or until Jorge gets home if he arrives before me. He usually arrives between 7:30pm and 7:45pm. So, for that time Jorge can cover for me, so to speak". Her description of Jorge 'covering for her' reveals the division of labour in the household, in which Jorge assists Andrea but does not take on the role of a primary caregiver.

I asked Andrea if Jorge knew all of Maurice's evening routine, and she replied: "Yes, yes, he knows all about how to look after Maurice. He knows how to change his nappy, he knows how to connect [the feeding tube] to the port, and how to give

[5] The mother-carers refer to personal assistants who support disabled children as *enfermeras* (nurses).

him his food". Then she mused on the feeding bag, which needs to be thoroughly cleaned and dried after Maurice is fed. She continued: "he knows… yes, he knows how the clean the bag… but no, he doesn't clean it. He has… well no, he hasn't bathed Maurice either. Wait, yes, he has, when he was little, before we had the nurse. Yes, he bathed him. When Maurice was little, a few months old." At the time of our conversation, Maurice was about to turn seven years old. Andrea, continued, distinguishing more explicitly between the kinds of tasks that others help with, and those which only she and the nurse do. She said of her husband and Maurice's aunts and uncles with whom they share the apartment building: "Yes, those are the people who support me in caring for Maurice. What do they do? Nothing more than keep an eye on him. He stays sitting there [pointing to the chair where Maurice was sitting], or if he falls asleep, they watch him, and if they have to pick him up, they can sit with him on their lap, but they do not give him food." Andrea has the assistance of a trusted, competent nurse for 12 hours daily, and her partner is well versed in the intricacies of Maurice's daily routine. Nonetheless, ultimate responsibility for Maurice's care lies with her. If the nurse calls in sick, it is Andrea who misses classes to stay home with Maurice. When she leaves Maurice in the care of his father, aunt or uncle, Andrea knows that it is unlikely he will have been fed or bathed before she gets home. Even though she has a paid auxiliary carer and a supportive partner, responsibility for care is concentrated with Andrea.

The gendered division of labour extends beyond the immediate family. In spite of having nursing support 12 hours per day, Andrea echoed Julia's feelings when she said: "I don't know how the other mothers do it. Ah well, I suppose it's because I don't have help. I can't say: "Ros, let's go out, tonight at nine I'll pick you up or we'll meet up somewhere. We can go out because my mum or my aunt or a neighbour is going to look after Maurice…" No, I can't do that. I can't. There are other mothers who have that good fortune. So… that's it. But yes, it's draining." Andrea imagines that other mothers who have more help from family receive it from their female relatives – mothers and aunts – as in the scenario of a night out that she creates. Even a female neighbour is considered a more likely source of support to care for her son than the child's own father. This echoes Julia's remarks about the lack of

family support she has – if she lived closer to family, she supposes that she would have regular help to care for Stefano and Ariana.

Patricia is in her early 30's and has two children, a 13-year-old son, Simon and a 7-year-old daughter, Dalia, who has CZS. She explained the difference between caring for a child with a disability from one without: "When you have a child without any syndromes, it's different. They start to become independent; they begin to feed themselves. But with Dalia, it is different. I have to make sure of everything, make sure she eats, do everything for her". Due to her impairments, Dalia requires more direct care from Patricia, and Patricia knows that this will continue beyond her childhood years.

Patricia went back to working as a teacher after Simon was born, but when Dalia was diagnosed with CZS, Patricia left work for good and became her full-time caregiver. When we met, Patricia was is in the process of separating from her children's father, and she told me that she was responsible for all of the children's care. Patricia does have the help of a female relative – her younger sister Selina lives with the family. She told me: "I have my sister, so I have more help. She is the only help I have around here. I have no one to watch the kids. Because of that you lose the opportunity to work, and it's just difficult to do things". She further clarified that her sister helps her with household chores like cooking and cleaning, and also entertains Dalia and keeps an eye on her while she rests or naps. Patricia is responsible for the children and the home, and her husband works to bring in a wage, and Selina assists Patricia with her tasks. But Selina also works outside the home, so she is not always available to help Patricia with the house or to keep an eye on Dalia. Patricia has access to support, but it is limited in scope and consistency. As a result, she feels the complete responsibility for the children lies with her.

The responsibility for caring for a child with CZS is placed firmly within the family unit. Within that, the division of labour is clearly gendered, with the mother as the primary caregiver. Even when they have help with domestic tasks, they feel alone in their responsibility for caring for the children and meeting the needs of the child with CZS and position themselves as the central figure in their child's care. When I

asked Andrea directly about the division of labour in her home, she said "As the mother, I am in charge of Maurice's care, with help from the nurse." Even though the family has access to the support of a professional care assistant, Andrea positions herself as the primary caregiver. She feels that the ultimate responsibility for Maurice's health and wellbeing lies with her.

Not only does the children's condition increase the complexity of their care, but it also raises the stakes. Mothers are preoccupied by the risk of infection and injury; they perceive their child to be more vulnerable than other children and know that a minor illness or injury can have lasting consequences. Mothers worry that others might not care for the child well, and this was reinforced by the words and actions of close family members.

One day when I was at Patricia's house her brother-in-law, Arturo, came over to visit. We all sat in the children's bedroom, out of the glare of the afternoon sun, and Patricia explained to him that I was a researcher and was interested in Dalia and her condition. We chatted for a while as Arturo held Dalia on his lap, and I asked him "what is it like being Dalia's uncle?" He thought for a while and said "I don't know how to answer that question… It's difficult because I don't know how to look after her, I don't know how to care for her properly. It scares me because something could happen to her while I was looking after her". Arturo echoes the mothers' fears about what might happen if they were to leave their child in someone's care who was not equipped to look after them.

Julia explained to me that feeding Stefano is a particularly complex aspect of his care. He doesn't open his mouth when she offers him a spoonful of food, so she has to persuade him to open his mouth, chew, and swallow. Keeping Stefano nourished takes time and patience. Julia has developed her technique over time to ensure that Stefano is well fed, and she is reticent to delegate that responsibility to others: "He doesn't open his mouth. So, I open it with my little hand. With me, he will eat all of his food, but with another person I know that they might not give him the entire portion." Julia elaborated, explaining that Stefano's father has tried to feed him, but was not able to do so. She said: "well for instance with his father, he's tried to feed Stefano and he – his own father – can't do it. Imagine if it were someone unknown".

Julia is afraid to delegate responsibility for feeding Stefano to anyone else in case they are unable to patiently feed him as she does. When Julia imagines "someone unknown" trying to feed Stefano, she is at least in part thinking of a professional care assistant or nurse. Unlike Patricia and Andrea, Julia has not sought nursing services to help with Stefano's care. Feeding is a key concern for Julia: "More than anything, it's about his food. Because carrying him, changing him is not so… look, it's still tiring, because he is a little heavy, and you are with him all day long. But anyway, it's his feeding that worries me the most." She continued: "So, that's why I haven't requested a nurse yet, because of the issue of feeding Stefano." Julia is afraid that Stefano would suffer if she delegated this task to the wrong person and they were unable or unwilling to feed him patiently. Her responsibility for his wellbeing extends beyond her direct care to the people she entrusts with assisting her. Andrea and Julia both distinguish between tasks that can be delegated to someone with limited specialist knowledge, and those that could cause harm to the child of done incorrectly (bathing and feeding) that cannot be so easily shared. The complexity of their child's care means that it is concentrated with the primary caregiver.

Ruptures to the maternal ideal

The concentration of care with the mother, through familist policy and the gendered division of labour, is common among carers of disabled children. Given the centrality of the mother figure, the idea of being a 'good mother' is often implicated in discourses around the care of disabled children. The 'unattainability' of motherhood is intensified by the coloniality of disability, as disabled children's future citizenship potential is placed under question and the mother is tasked with 'overcoming' the impairment(s) through intensive intervention. Mother-carers ability to meet their child's needs is constrained by societal ableism. As a result, it is impossible to achieve the standard of care mothers feel responsible to provide without external input. For the child's needs to be met and the mother to feel positive about her role and the relationship between her and the child, state support is essential (Hernández Galeano and Puerta Gil, 2014). Identifying a need for external support and making a demand for input (from family, community, the

state) becomes an effective way to resist the unrealistic expectation of individualised motherhood.

Runswick-Cole and Ryan (2019) propose "'unmothering' as a means of breaking away from traditional patriarchal, ableist, classed and raced notions of 'good mothering'"(p. 1127). The authors are activists, academics, and mothers of disabled children. In 2013, Ryan's son Connor died in an NHS facility as a result of neglect by the NHS Trust and staff responsible for his care (Runswick-Cole and Ryan, 2019). In the context of mothers' activism on behalf of their children, they discuss the organic, collective demand for justice beyond kinship ties that arose in response to Connor's death, putting forwards a refutation of the individualisation of responsibility for care and advocacy to the mother (Ryan, 2017; Runswick-Cole and Ryan, 2019). The authors acknowledge the specificity of the context that surrounded the campaign, particularly the fact that it was led by a highly educated and well-connected professional (Ryan).

The participants in my research also reject the individualising notion of 'good mothering' and make demands of the state to protect their child's human rights. Reading the Runswick-Cole and Ryan's account, I found myself questioning what 'unmothering disabled children' might mean for poor, working class mothers in the Global South. I attempt to answer this by bringing the notion of unmothering into dialogue with literature on the politicization of motherhood and care as resistance from Latin America. Mateo Medina (2013) arrives at an understanding of how mothers transform their role into a political one through an analysis of the *Madres de Soacha*, a group of marginalised (rural, poor, campesina) women whose children were disappeared and killed by state forces during the Colombian armed conflict. Quintela and Biroli (2022) bring together black feminist theory with empirical observations about the activism of poor, majority black mothers following their child's murder by the Brazilian police to develop their theorisation of care as resistance to state violence. Díaz Alzate and Ramírez Taborda (2022) point out that "women bear the double blame, namely, that of being caregivers who fail to meet the comprehensive needs of children with disabilities and that of being women who are always expected to care." Mateo Medina (2013) and Quintela and Biroli (2022)

make more explicit what Díaz Alzate and Ramírez Taborda allude to; that poor, often racialised women with limited education and access to resources are at once expected to dedicate themselves to care work and structurally constrained from fulfilling the maternal ideal. The mothers in Mateo Medina and Quintela and Biroli's research are politicised in response to direct state violence against a child, which may be more visible and legible to their family and the wider public as violence. Runswick-Cole and Ryan (2019) show that structural violence that produces harm in a more distant manner can also incite a process of politicisation. In each of these cases however, mothers confront situations of structural violence against their children and themselves that ultimately deprives them of their ability to care for their child. State neglect and violence makes visible the coloniality of being; their children are considered less than human on the basis of their race, gender, ability, and socio-economic status, and punished or neglected as a result. This creates a rupture with the maternal ideal, which leads to a reconceptualization of the maternal role as a political one and of care as a form of resistance (Mateo Medina, 2013; Runswick-Cole and Ryan, 2019; Quintela and Biroli, 2022).

In the case of Zika and CZS, the impact of structural violence is more indirect (Scott, 2020). Entrenched inequalities expose along the lines of socio-economic status, gender, race, migration status and ability mean that exposure to infectious diseases such as Zika, access to diagnostic services, reproductive health and rights, and assistive technologies, are all stratified. Impairment by in-utero Zika infection stems from a failure by the state to address inequalities and intervene to prevent infection, and their disability results from the way that societal systems and structures are set up to cater to normative citizens and exclude those who fall outside of the 'norm'. The coloniality of being results in the dehumanisation of disabled people, including children with CZS, and the violation of their rights (to health and wellbeing, education, and a dignified life). Motherhood in a political stance under conditions of structural violence is concerned with the assertion of personhood and resistance to dehumanisation. Williamson (2024) has shown that engagement in habilitative care can be a form of resistance against the denial of children with CZS's futures, and an assertion of personhood. I expand on this by

exploring the dehumanisation of children with CZS from the perspective of the coloniality of being.

I approached this research with an interest in uncovering the structural factors that facilitated or inhibited the full exercise of rights for mothers and children affected by Zika. Nonetheless, I was curious about whether participants were concerned with living up to an imagined maternal ideal. I did not directly introduce the idea, but remained attentive to possibility that a participant might introduce topics in line with this framing. Flexible, ethnographic data collection allows space for participants to introduce ideas that challenge the researcher, and reflexive analysis grounded in a critical, constructivist paradigm requires that we look for what is absent as well as what is present in the data we collect. In line with this, while I remained attentive to the possibility that mothers may introduce the notion of 'good' or 'bad' motherhood, I found that they did not. Mothers want to give their child a good quality of life, make them comfortable, avoid injuries and illnesses as much as possible and promote their participation. However, these wishes come in the form of a demand for more robust external support. They do feel the weight of the world on their shoulders, but they do not accept this as the way things have to be.

In the context of raising children with CZS, mothers' ability to live up to the maternal ideal is constrained by the lack of support from the state combined with ableism and familist welfare policies. This constitutes structural violence and makes it impossible for mother-carers to live up to the imagined standard of a 'good mother'. In areas of Brazil where a high proportion of Zika cases were concentrated (particularly the northeast), mothers have formed political/ advocacy organisations and make explicit, collective demands for rights and services (Dias, Berger and Lovisi, 2020). In the Brazilian context the leaders of these groups have become 'militant mothers' through the reconceptualization of their role in the face of structural violence (Pinheiro and Longhi, 2017; Pinheiro, 2018; Scott, 2020). In Colombia, where there were fewer cases of CZS that are distributed more evenly across the country, mother-carers resistance takes place on a smaller scale. Mothers still wish to make their child comfortable, ensure they have good quality of life and making sure their basic needs are met to promote good health, but they

nonetheless push back on individualising notions of 'good' mothering in a number of different ways. As Runswick-Cole and Ryan (2019) highlight, unmothering does not mean denying or devaluing the role of the mother, but seeks to problematise the familist logic that isolates mothers in this role. The mother-carers in this research have adopted a political stance towards care work and make demands of the state to provide services and resources that would alleviate the pressure on as the primary caregiver to a child with CZS. Rather than striving to live up to patriarchal, ableist, classed and raced notions of 'good motherhood', participants demand good care for their child.

Redefining caring as a skill

While some mothers expressed that it takes a certain kind of person to care for a child with a disability (referencing patience, caring nature), they did make clear that it was possible for someone with minimal extant knowledge to learn to care for a child with CZS. Rather than being an inherently 'motherly' ability, they understand caring as a set of skills that can be taught and learned. The first example of this was their own journey – from knowing nothing about CZS or complex disability, through a process of learning by doing and learning from others to the level of capability they had achieved by the time I met them.

Maurice is Andrea's first and only child, and before she was a mother, she didn't have any existing experience of caring for someone with a disability. She explained that despite her initial lack of knowledge and the limited support available, she had learned to care for Maurice. She said: "I learned to do everything for Maurice. You learn by doing." Her confidence had increased over time as she gained more experience of looking after Maurice. "I know a little of everything, with the amount of time I have spent with Maurice already I can look after him, and I would have the courage to care for another little patient as well". Reflecting on the process she went through to learn to care for Maurice, Andrea said: "I'd like it if there was training for mother-carers. Right now, we have to teach ourselves to care for them." Andrea identifies practice and dedication, rather than maternal instinct, as essential to the process of learning to care for a child with CZS. By referring to her capability to care for another 'little patient', Andrea pushes back on the idea that

only a child's own mother is equipped to provide them with good care – it is experience and willingness to learn that makes someone a good carer, and that can and does exist outside the immediate family. She also calls for more external support for mother-carers to learn how to care for children with complex needs.

Mothers who have sought external support for their child oversee and coordinate their child's care. They hold themselves responsible for the care provided by others under their supervision. Andrea reinforced the importance of practice and spending time with the child to learning how to care for them when she explained how Isabela has learned to care for Maurice. In a group discussion, some of the other mothers raised concerns about leaving the child with a nurse in case they did not care for them properly. Andrea concurred that she would not leave Maurice with a new caregiver right away. She explained that "in my view, a new person would need a minimum of one month to learn to look after Maurice, and they would need to watch me care for him first so that they can learn how it is done." Andrea has 'learned by doing' and can impart her expertise to another through demonstrating how she cares for Maurice. Even though Isabela is a trained professional, Andrea believes that spending time with the child is essential, as any caregiver needs to learn their specific care needs and routine in order to provide them with good care. She said: "Isabela has already spent a long time with Maurice, she knows what he wants when he cries, if he is hungry, if he needs to poop, if he is tired, she knows where she needs to take him [for therapies], when to put him to bed, she knows all of that." Care is highly personalised, and the relationship between the patient and the caregiver is central. Andrea explained that Isabela's role in Maurice's care only worked because Maurice "accepts her". The rapport and respect between the mother, child and nurse is key to making this relationship work. Before Isabela was assigned to them, the service used to send different nurses and there was no consistency. It was also harder for Andrea, Maurice, and the nurse to build up a good rapport when they kept changing. "Well, there have definitely been nurses who have not been a good fit, that haven't had that 'feeling, Maurice kex on crying, and so I decide to change the nurse because there is not an affinity between them. I give them time to get to know each other, it's not like the first day Maurice is crying and the second day I say, "this nurse is no good", no, no,

not like that – the idea is that they get to know each other". While Andrea talks about the nurse and patient needing to accept one another, in practice, Maurice's acceptance of the nurse is mediated through Andrea's acceptance or rejection of them – she is the one who can enact a change in the service provision by contacting the company. Her assessment of the nurses is based on whether she believes they are providing Maurice with good care. In order to make such an assessment she first has to teach and then observe them caring for Maurice, which takes time. When mother-carers seek outside help with their child's care, they delegate some tasks, and their role shifts to ensuring that the child receives good care.

I had the opportunity to observe the process of a mother teaching nurses how to care for a child with CZS when Patricia was first provided with nurses to help her care for Dalia. While Andrea has support from the same nurse for twelve hours each day, Patricia has twenty-four-hour support provided by three nurses on rotation. When Patricia was finally provided with nursing services, the manager of the nursing company came to the home to do an assessment of the family's needs and living arrangements and to organise the provision of the service. She gave Patricia information about the company and went through a series of ground rules for the working relationship between families and nurses. She asked Patricia if it had taken long for her insurer to grant her cover for the service, and Patricia told her it had done, that in fact she had been trying for years. Patricia told the manager: "It's not that I don't want to care for my daughter, I just need help." This appeared to be a familiar sentiment to the manager and the nurse, and they told her that they understood.

I visited her at home on the day this provision started, and observed Patricia showing Laura, the nurse, how she cared for Dalia. Patricia prepared lunch and Laura carried Dalia through from her bedroom to the living room and put her in her chair ready to eat. Patricia said, "I'll show you first how I give her lunch." Laura watched while Patricia demonstrated how she cuts up the meat on Dalia's plate into very small pieces, then prepares a small spoonful of food with some rice and meat. She asks Dalia to open her mouth, and then encourages her to chew and swallow. Before offering her another mouthful of food, she checks that Dalia has swallowed

the last one. If she is fed too quickly, Dalia sometimes spits out the food in her mouth. There is also a risk that she might choke or vomit, so the pacing of her meal is important. After a while, Patricia handed Laura the tray and she took over feeding Dalia. Patricia observed Laura's progress as she prepared a drink for Dalia, adding ice and explaining "she won't drink it unless it is ice cold." Patricia both demonstrated and explained how she feeds Dalia, and then supervised Laura as she put what she had seen into practice. She repeated this process with each of the three nurses, and was especially attentive to their care during the first few weeks. The next time I visited while Laura was there, she fed Dalia her entire lunch while Patricia ate her own meal and cleared up the plates. A few months later, I accompanied Patricia to the office of the Secretary for Education, where she was trying to find a suitable school to enrol Dalia for the coming school year. One of the other nurses, Melissa, had stayed at home with Dalia and Patricia phoned her in the early afternoon to check in. Once she got off the phone, she told me that Melissa reported that Dalia had been well behaved and had eaten all of her lunch. Patricia explained and demonstrated different aspects of Dalia's care to her new nurses, then allowed them to practice under her supervision. Once she was satisfied with their performance, she felt confident leaving Dalia in their care while she went out to run errands. One of the nurses that was assigned to them in the first few weeks ended up not being a good fit – she wasn't able to work independently and referred to Patricia constantly to check what needed to be done, even after being shown and supervised in the first few weeks. Patricia did not think that she was capable of putting in the effort to learn how to care for Dalia properly, and requested that the company send someone new. After that, a new nurse joined the other two in a permanent rotation. Over time, Patricia began to trust the three regular nurses to care for Dalia independently. As with Andrea, Patricia assessed the quality of care the three nurses were providing for her daughter and found one of them to be lacking. The was invested in ensuring that all of the nurses working with her daughter were able to learn to provide good care for Dalia. Julia is hesitant to request nursing services for exactly this reason – she is worried they won't provide good care for Stefano.

Through their experiences of teaching the nurses how to care for their children, Patricia and Andrea have re-defined caring as a skill to be learned and honed over time. Mothers reject the maternal ideal that concentrates all responsibility for care with the mother, and prioritise good care provided by competent, dependable people. Whereas a 'good mother' is silently stoic, these mothers have made a demand for support by fighting for nursing services. Patricia rejects the role of the endlessly resilient, uncomplaining mother when she opens up to the nursing service manager about needing help. While the 'good mother' takes responsibility for all aspects of care, these women have delegated care and take responsibility instead for ensuring the quality of care provided by others to their child, by training and supervising them.

"I'm still your mother"

Mothers who have managed to get access to external support do not feel that handing over responsibility for some aspects of care is in conflict with their role as the primary caregiver. They accept responsibility for their child's wellbeing without accepting neglect, isolation and doing so in constrained circumstances.

Patricia told me she had prayed to God to help her in the process of getting access to nursing support. She said, "I was so tired; I couldn't carry on like that much longer." Patricia had reached breaking point – Dalia was getting bigger and heavier, and her marriage ending left her with even less support than before. It had become impossible to fulfil the maternal ideal and provide her daughter with good care in the absence of any support.

Around a month after the nursing service began, Patricia joked to me that Dalia had lost interest in her, saying "she only wants the nurses now!" She was cooking lunch, and paused to check on Dalia, who was in her bedroom resting on her bed, with the nurse sitting beside her. When Patricia entered the room, Dalia continued watching the nurse and did not respond to her mother. Patricia returned to the kitchen and said, "since the nurses came, she doesn't want me anymore". She called to Dalia in the next room: "okay my love, I'll stop cooking too, shall I? Since you don't want me around." Her tone was light, and she made these joking remarks in front of the

nurse, who laughed along. Nonetheless, I wondered if she did feel some conflict or tension about sharing the role of being Dalia's primary caregiver after almost seven years of doing it on her own. We left the house so that Patricia could run an errand, and I took the opportunity to ask her how she felt about Dalia 'preferring' attention from the nurses. When I brought up her earlier jokes, she said, "I told her 'I'm still your mother', and I'm really glad that she likes the nurses and accepts their care." Like Andrea, Patricia emphasises the centrality of relationships to care; Dalia's acceptance of the nurses is an important element of the working relationship and, as with Andrea, likely reflects Patricia's own acceptance of the nurses and the situation. In joking about no longer making everyone's lunch, and emphasising that she is still Dalia's mother, Patricia highlights the role that she continues to play in Dalia's care – cooking her nutritious meals, as well as showing her affection, coordinating the nursing and transport services, working with the nurses on Dalia's daily personal care, and making healthcare appointments. She acknowledges the benefit of the nursing service not only to Dalia but to herself ("it's better for me"), demonstrating that rejecting self-sacrifice and sharing responsibilities is not incompatible with motherhood and being a good caregiver. She has reconceptualised her role as mother and primary caregiver in the context of much needed outside support for her and Dalia.

Reciprocity of care

Mother-carers reject the notion that they are only providers of care and their children are solely recipients of care. This framing constructs disabled children as drains on their mother's energy and reinforces the familist and patriarchal logic that positions women as 'natural' caregivers. The mother-carers in Pinheiro's (2018) research also rejected this unidirectional understanding of care, explaining that they derived strength from their child's love, and that they also received care from other mother-carers within activist organisations and networks. These mothers identify that the burden on them originates with the lack of support from the state. They have come to understand through years of experience that their wellbeing is intertwined with that of their child, and that they need support to promote both their own wellbeing and that of their child. Speaking of their first few months receiving

round the clock nursing care, Patricia said: “It’s better this way for her and I feel better, I’m more rested and it’s better for me.” Patricia rejects the notion that she provides wellbeing (sacrificing her own in the process), and her daughter receives it. Rather, their wellbeing is intertwined and proper support from the state can benefit them both.

Andrea has also reconciled Maurice’s care needs with her own needs and wellbeing. Before she became pregnant with Maurice, Andrea worked as a technician. When the extent of Maurice’s impairments became clear to her shortly after his birth, Andrea decided not to return to work, and has been his full-time caregiver ever since. The sacrifice that Andrea made when she gave up working is clear, but since she was granted nursing services for Maurice, she has begun to re-imagine their future. She is studying and plans to look for work once she has completed the course. She said: “What is it that I want? To work, so that I can make an income. That’s the part of me that is frustrated as a woman, as a person, wanting to achieve my own goals, my own dreams, that are quite independent from what I do with Maurice. But I see myself doing that, achieving that, I see myself doing that with him.” Rather than positioning Maurice’s care needs in opposition to her aspirations to work and make an income, Andrea conceptualises her wellbeing as being interlinked with that of Maurice. Rather than giving up her dreams and aspirations permanently, she has fought for access to services that promote both of their wellbeing and enabled her to study while knowing that Maurice is well cared for. She believes that her son will be better off if she is more fulfilled by studying and work and can make an income to support the family. Having access to a nurse who supports her to care for Maurice has enabled Andrea to re-imagine a future in which she can study and work whilst giving Maurice the best care and ensuring that he is comfortable and remains in good health.

In response to the lack of direct support for mother-carers of disabled children, they fight for services designated for their children in order to make their own lives easier and also benefit the child. The provision of nursing services to the child can afford the mother-carers a greater degree of independence, as she has someone with whom to share the responsibility of caring for the child. Rather than seeing

themselves as providers of wellbeing and their children as recipients (as in a familist logic) they see their wellbeing intertwined with that of their child, and position the state as an actor in the network of care relationships that (should) support wellbeing for disabled children and their families. I will explore interconnected wellbeing further on the chapter on disability and debility.

Fighting has a political character

Patricia told me that as soon as she found out that Dalia would be born with a disability, she searched online: *'¿Qué derechos tiene un niño con discapacidad?'* ('what rights do children with disabilities have?') and as she read the results, she said to herself "my daughter is going to have everything that she needs". Patricia identified the health insurance provider (EPS) as a key actor in ensuring that her daughters rights were protected. When she was first researching disability rights, she wondered "what the rights are for people with disabilities in relation to the EPS?". She continued searching and found the rights of patients under the EPS and she said, "everything I had thought of – it was right there. The right to health, right to education, right to dignity." She continued: "the EPS knows that the child has the right to at minimum… the right to a dignified life." In Patricia's analysis, it is the state who must deliver on the rights of people with disabilities, through policies and a health system that uphold human rights. When the state fails to protect the rights of disabled children, mothers are left to hold it to account. Patricia told me about the difficulties she had encountered while trying to get specialist appointments, medications and supplies for Dalia. She said: "you can't really blame the medics for the lack of health access, there is an [EPS] auditor that stands as a barrier between what medics say and what the EPS will provide. The only way you get access to things is by applying pressure." The right to health is mediated through a private entity that the state has placed in charge of providing health coverage to the Colombian population. Denials and delays are a regular occurrence (I will discuss this more in the next chapter), and mothers have to apply pressure and fight for access. Patricia refers to this process as a "daily fight for health" that she engages in on Dalia's behalf. Andrea also uses the language of a 'fight', and expands on the cause of her struggle: "It's a constant fight. It's a cultural issue,

things are not accessible. It affects you emotionally, I don't have emotional support. Sometimes I don't want to do it anymore, going to appointments, fighting with the EPS, it's a big failure." Andrea points to the societal failure that makes services inaccessible for people with disabilities and overburdens carers – her fight is political because she faces societal barriers with Maurice. Within the constraints of the health care system, mothers continue to fight to give their child dignity and good quality of life. Julia explained that part of accepting Stefano's condition was accepting that she would have to fight for him in order to get access to services. "I have accepted that my son has a disability, and that I have to fight for him. I have to fight." For these mothers, their fight has a political, rather than self-sacrificial, character. As Pinheiro (2018) points out, the fight for their children's rights shifts the site of mothering from the private sphere of the family into the public sphere. Mothers subvert their role as intermediaries between the state and the family to make demands of the state. In doing so, they assert their child's personhood publicly.

Concluding remarks

In this chapter I have shown how an examination of the dynamics of gendered care work can illuminate the tension between the coloniality of being and the assertion of personhood for disabled children. Disability policy in Colombia is explicitly familist, delegating responsibility for care and upholding the rights of disabled people to family caregivers. In the context of a gender order that assigns responsibility for reproductive labour to women, this means that care for children with CZS in Barranquilla is highly concentrated with mothers, even when they live with partners. Within the coloniality of being, the humanity, and thus the personhood and citizenship, of disabled people is denied by the state, and as such, their rights are neglected. Mothers recognise that this structural violence has material consequences for their child. The unattainable nature of 'good motherhood' is intensified for mother-carers of disabled children, causing a rupture with the maternal ideal. I have developed the theory of 'unmothering' from the margins' through an examination of mother-carers responses to such a rupture. They have redefined care not as a maternal virtue but as a skill that can be taught

and learned. This has enabled them to reconcile delegating care to others with their responsibility for the child's wellbeing and their affective care for them. Mother-carers reject the notion that their children are recipients of care only and that they are providers, arriving at an understanding of care as reciprocal and pointing out that getting good care for their child also benefits their own wellbeing. They engage in a political fight to gain access to good care for their child, making demands of the state to provide. Investing in their child's care represents an assertion of the child's personhood, resisting the coloniality of being. By making demands of the state for good care, they assert their child's personhood in the public sphere.

Chapter 5: Self-management of health

Introduction

As I have shown in Chapter 4, mothers are the primary caregivers for children with CZS. Their role extends far beyond the provision of direct personal care within the private sphere of the home. Their children require specialist medical and therapeutic interventions, and mothers navigate systems on behalf of their children. In the process, they frequently encounter barriers to timely access to healthcare, education, and welfare for their child. Barriers and facilitators have received significant attention in the literature, but agency and responses to barriers less so. I suggest that the primary caregiver is one of the main facilitators to access. I bring together Menéndez' concept of *autoatención* (self-management) with Madden's conceptualisation of cultural health capital, adopting a feminist perspective to explore how mother-carers respond to barriers and negotiate access to health care and education on behalf of their child. They draw together formal and informal spaces of attention and care, make use of both biomedical and alternative interventions, and share information about how they manage their child's health with other mother-carers. This use of diverse strategies for promoting their child's health, and the importance of community and peer support demonstrates a rejection of the individualising biomedical model of health. The role of community and collective approaches to promoting health leads to a discussion of experiential knowledge and the formation of an epistemic community around CZS.

Standards for follow up and treatment of CZS

As discussed in Chapter 1, clinical guidelines for the assessment, diagnosis and follow up of children with CZS were published in 2016 (Minsalud, 2016d). The guidelines require that children with nervous system injuries caused by in-utero Zika infection receive integrated care from a multidisciplinary team. They also emphasise that in addition to clinical interventions, families should be given clear information and education about the condition and that psychosocial support should be made available for caregivers.

The available guidelines only cover the first two years of life, and further guidelines for clinical management have not been produced. Six years on from the publication of these guidelines, the children's care is fragmented and psychosocial support for the families has not materialised. None of the families in this research received support from a social worker, and several of the mother-carers told me that they had never received any psychological support. In terms of their children's care, monitoring and therapeutic interventions, mother-carers encountered numerous barriers, delays and denials to securing access to timely and appropriate interventions. The focus of this chapter is exploring how they respond to these challenges.

Barriers, delays and denials

My focus on responding to barriers originates from a comment a participant made during data collection. In a group discussion, Patricia was explaining to another mother how she had got nursing care at home for her daughter. She said, "You get a prescription from the doctor and take it into the EPS [health insurance provider], and it gets denied. Then you mount a petition, and they say no. Then you go on to seek a court order". For Patricia and the other mothers, the barrier or denial is often the starting point of the negotiation of care, not the end.

Qualitative global public health research has illuminated the barriers and facilitators that parents of children with disabilities face when navigating these systems. Mothers in Brazil reported that long distances to rehabilitation facilities and lack of appropriate transport options were barriers to attendance (Albuquerque *et al.*, 2019; Campos *et al.*, 2020). The high cost of medications, cuts to services, and a lack of suitably specialised staff and services were all noted as barriers to comprehensive health care for children with CZS (Albuquerque *et al.*, 2019; Campos *et al.*, 2020). Chasing referrals and coordinating between fragmented services was time consuming, and long delays and waiting times delayed their child's access to care (Albuquerque *et al.*, 2019). Family support with childcare was identified as a facilitator to accessing healthcare and therapeutic services on behalf of their child (Campos *et al.*, 2020).

The finding that mothers spend significant time chasing referrals and coordinating services (Albuquerque *et al.*, 2019) reveals the essential role that mother-carers themselves play in facilitating access, however analysis of the role that the carer themself plays in these interactions is limited, and their agency is neglected. Patients' or carers' own efforts to gain access are rarely discussed as facilitators in their own right, and consideration of barriers often neglect patients or carers responses to them. Identifying barriers is crucial for making policy changes and designing interventions, but in the moment, it is the reaction to a barrier or denial that determines whether and how things move forward. In Chapter 4 I highlighted the structural forces that shape experiences of motherhood and care in relation to CZS. Together with literature on barriers and facilitators to access (in which the presence of barriers often looms large while facilitators are few, far between, or imagined rather than extant) this paints an important but incomplete picture. In analyses of the intersecting disadvantages that mother-carers of children with disabilities in impoverished, urban settings experience, "'misery accounts' are not sufficient… we also need to understand how mothers manoeuvre, adapt, act and react in such a context" (van der Mark *et al.*, 2019, p. 1). In addition to illuminating under-explored practices, in focusing on mother-carers as facilitators, I respond to the call to move away from "damage-centred" research (Tuck, 2009), and attempt to denaturalise the challenges these families face. I aim to put a spotlight back on responses to barriers, which in my view invites a discussion of agency and resistance in negotiating care. In seeking to address this gap around responses to barriers, I intend build on Shim (2010) and Madden's (2015) conceptualisations of cultural health capital and put these into dialogue with Menéndez' concept of *autoatención*.

Autoatención

Menéndez's conceptualisation of *autoatención* (self-management) is empirically grounded in his research on different systems and practices of health and wellbeing in Latin America. *Autoatención* describes the ways that individual subjects and communities attend to their 'bio-social reproduction' through self-management of the 'health/illness/care process' (Menéndez, 2003, 2018).

Autoatención acknowledges structural vulnerabilities that communities face in relation to the prevention of illness and attainment of good health, and within that understanding, continues to draw our attention to patient agency. Menéndez posits that the patient or carer is the 'nucleus' of attention to health; they are active agents who bring together different health resources in order to address their ailments, even when those different resources may appear incompatible (Menéndez, 2003, 2018). As such, *autoatención* is not separate from formal health care provision, but essential to the efficacy of health services and the translation of resources into health outcomes (Menéndez, 2003). Weingast (2016) uses *autoatención* to analyse how caregivers manage childhood illnesses, and her contributions to the concept are useful in developing my own application. She shows how *autoatención* disrupts the notion that care is a lay practice provided by family in the domestic sphere, distinct from (medical) attention delivered by professionals in hospitals and clinics, as family caregivers take a central role in coordinating diverse health care resources (Weingast, 2016). As such, the distinction between the public and private spheres in the context of the gendered division of care work is disrupted by practices of *autoatención* (Weingast, 2016).

Menéndez's theory positions self-management as key to the efficacy of formal health care provision, in contrast to Euro-American theorisations of self-management as supplementary to formal health care provision (Martínez *et al.*, 2021). In the Euro-American medical and nursing literature, self-management[6] is understood through a frame of individual responsibility for one's own health, even in the context of peer support groups (Richard and Shea, 2011; Martínez *et al.*, 2021). In contrast, Menéndez (2009) explicitly frames *autoatención* as a way that groups and communities attend to their collective bio-social reproduction. As I have shown in Chapter 4, the mother-carers in this research understand care to be a reciprocal social process, and resist the individualisation of care within the private sphere of the family. Based on this, I use *autoatención* as a frame to explore how they engage

[6] Self-management and self-care are often used interchangeably in this body of work, see (Richard and Shea, 2011; Martínez *et al.*, 2021).

in collective practices of self-management in their interactions with the health system.

Menéndez refers to self-management of one's own "illness trajectory" or "patient journey" through practices of *autoatención* (Menéndez, 2003). This expression brings to mind a particular type of patient journey which is familiar to many working class Colombians: *el paseo de la muerte*. This refers to cases in which a patient experiencing acute illness is turned away from health services or sent to a different location, often due to their inability to pay for services or because their insurance is not accepted at a particular facility, and dies while in transit before receiving care (Navarrete Sánchez, 2008; Marsiglia Morales, 2015). A number of participants explained this phenomenon to me and told me they knew of people who had died under similar circumstances. Catalina is a foster mother to five young boys, all of whom have impairments. During an interview, she told me that one of the boys was enrolled in a different health insurance scheme to the rest of the family as he had been born in a different region of the country. "The situation with the health insurance, its complicated. Look, when he gets sick, we go out and look for a clinic, but no one wants to see him. They say, "his EPS does not cover care at this clinic." It's a terrible thing, *como se dice, 'un paseo de la muerte'* [as they say, 'the walk to death']. Yes, it's happened to us. We thank God that he did not die, but yes, it has happened to us, with the children". *El paseo de la muerte* looms large for mother-carers and provides important context for understanding *autoatención* in relation to a formal health system that fails in effectively managing patient journeys, with tragic consequences. *El paseo de la muerte* represents the most extreme end of negative patient journeys, but mother-carers experience more mundane forms nearly daily.

Cultural health capital

Patient agency is central to *autoatención*, and cultural health capital offers a framework to understand how patients and carers enact their agency as they confront diverse barriers to the realisation of good health and wellbeing. Shim (2010) develops the concept of cultural health capital from Bourdieu's social capital,

and defines cultural health capital as "a specialized form of cultural capital that can be leveraged in health care contexts to effectively engage with medical providers." Cultural health capital consists of "the repertoire of cultural skills, verbal and nonverbal competencies, attitudes and behaviours, and interactional styles…that, when deployed, may result in more optimal health care relationships" (Shim, 2010, p. 1). Shim stresses that what constitutes cultural health capital depends very much on the healthcare system of a given context.

Madden (2015) expands Shim's concept of cultural health capital in a number of ways that make her conceptualisation particularly resonant for my own analysis. Firstly, Madden considers health seeking in informal and alternative spaces, and secondly, her research involves at familial carers and advocates who use their own cultural health capital to leverage care on behalf of others. In Madden's (2015) study of healthcare navigation among Mexican migrants in the USA, she adopts a lens of critical race theory in her analysis in order to highlight the structural exclusion of migrants from the healthcare system based on their ethnic background and migration status, which creates economic, linguistic, and political barriers to access. She finds that health care professionals assume that Mexican migrants lack the cultural skills to successfully navigate these systems and institutions, whose norms and language 'belong to' the dominant culture. However, Madden shows that patients and their advocates respond to barriers by drawing on diverse "cultural resources" to gain access through the official channels or alternative means. Madden suggests that a different set of skills is required to navigate alternate or parallel health care spaces than dominant, mainstream ones, and that marginalised communities develop different forms of cultural health capital to gain access to different spaces, with varying degrees of success.

Cultural resources for enacting *autoatención*

In Madden's (2015) conceptualisation, different health care 'spaces' are considered to be quite distinct, and patients deploy diverse cultural resources in order to access them, demonstrating agency. The theory of *autoatención* represents a significant advancement in terms of the role of the patient, as Menéndez finds that

it is patients themselves that bring different 'spaces' into contact as they move between them and use one to supplement one another (Menéndez, 2018). The patient or carer not only uses and combines resources from different settings, but "reconstitutes and organizes these forms of attention in activities of 'self-attention'" (Menéndez, 2018, pp. 190–191). In my analysis, I bring together cultural health capital with *autoatención* to demonstrate the specific cultural resources that patients and carers use to reconstitute health care spaces. Following Weingast (2016), I adopt a feminist perspective, viewing *autoatención* as a facet of gendered reproductive labour.

Navigating health-treatment-care from a position of social disadvantage

In contrast to the professionals with whom they enter into negotiations, (the doctors, therapists, service managers and insurance auditors), the mother-carers in this research are young, with limited education, and often racialised or migrants, and they come from lower income backgrounds. Professionals can be patronising, dismissive, obstructive, or hostile towards them at times. One morning I met Patricia, Dalia, and the nurse at a clinic, hoping to observe an appointment with the paediatrician. At that time, most COVID-19 restrictions had been lifted, but the doctor did not allow me into the consultation room, citing the rule that only one person was allowed to accompany each patient. I sat in the waiting area with Dalia's nurse, and after the appointment Patricia re-joined us. She explained that other doctors at that clinic usually allowed the nurse to enter the consultation with them, but this paediatrician was often brusque and dismissive towards them. Because of their different positionalities, mothers believe that professionals expect them to be passive or even ignorant. Patricia told me about another time when she stood up for herself at the hospital and was accused of being rude and aggressive. Dalia had been diagnosed with bronchopneumonia and needed to be admitted. Patricia told me that the room they were taken to in the hospital was damp and smelled of mould. Patricia objected, pointing out that the mould could worsen Dalia's condition, and said she wasn't going to leave her in an unsuitable room.

Recounting her words to the hospital staff, she told me: “How am I going to leave my daughter here when she has come in with a respiratory illness? No, I can’t put my daughter here, so I’m leaving. No, not just for us, no child should be put here in this area, this area smells horrible.” When she spoke to someone higher up in the hospital, they asked “okay, what happened here? You were the one who was behaving rudely? That’s what the staff member told me”. Patricia replied that she had not been rude, but simply stated the facts that the room was unsuitable and posed a risk to her daughter’s health. Her assertiveness and commitment to her daughter’s wellbeing was read as aggressive by staff who expected her to accept the room without a fuss.

Such attitudes were also reflected in my conversations with local disability charities and organisations. In a summary of my discussions with these key informants, I wrote: “how people speak about parents is really interesting. When they refer to parents as a group, they are often described as fairly passive, lacking the skills and knowledge to care for their child and get them what they need. But when someone tells me about an individual parent, they are described as super, amazing, and that they can’t do enough for their child. This seems to overlap with socioeconomic status as well – those who have the means to provide lots of inputs, resources, and adjustments are considered ‘amazing’ and those who don’t are either passive or it’s acknowledged that it’s very difficult for them to provide”.

Practices of *autoatención* differ among populations along the lines of socioeconomic status, education, race and ethnicity, rural and urban location, and religious belief (Menéndez, 2003). The practice of *autoatención* in middle class families is more legible to service providers, who typically occupy a similar class position, and is understood as a legitimate form of care. Poor and marginalised parents are also engaged in *autoatención* on behalf of their children, but their efforts are less visible and may be ignored or undermined. At one centre, a school with integrated rehabilitation that serves lower income families, a staff member told me that the ‘silver lining’ of the COVID-19 pandemic was that parents had to become actively involved in their child’s therapies by doing physio stretches and stimulation activities with them at home, rather than just “dropping them off and

not worrying about that part of their care" since it was provided at school. Three of the children in my research had been enrolled at this school at various times. I knew that while they were at school, their mothers were caring for their other children, doing household chores, working, picking up prescriptions or in education. When the children returned from school, their mothers fed them, entertained them, and did therapeutic exercises with them. An analysis based on the concept of *autoatención* invites us to re-consider the distinction between 'care' as an unskilled, affective process carried out in the domestic sphere, and 'attention' as a professional service provided in facilities (Weingast, 2016). This approach unsettles the notion that facilities are exclusive sites of expertise, and together with an analysis of cultural health capital, it is clear that patients and carers develop extensive knowledge of health systems and services, analyse interactions, and deploy information and skills to gain access.

Unsettling the boundaries between different spaces of care and attention to health is particularly relevant when bringing cultural health capital and *autoatención* into dialogue. Madden (2015) suggests a distinction between the cultural health capital that one needs to access formal or mainstream systems, and informal or marginal ones. Indeed, it is apparent that marginalised groups develop at once broad and yet specialised cultural health capital based on their positionality in relation to the health systems that exclude them. However, in my analysis the distinction between different types of cultural health capital is not as clear cut. Facing structural exclusion and system barriers, mothers move between different systems and spaces. Here the broader concept of *autoatención* is particularly pertinent, as it places the patient or carer at the centre, forging interactions between different services, resources and information to bring about a given health outcome. Menéndez critiques the notion that practices of *autoatención* within and outside of formal, biomedical health care systems are antagonistic, instead finding that they represent "transactional articulations between the different forms of care" (2003, p. 186). I have found that mother-carers of children with CZS use official channels to overcome barriers but also employ alternative strategies. Utilising diverse forms of cultural health capital, they bring different systems into contact and create routes between them. In so doing, they unsettle the notion that care is exclusive to the

domestic sphere, as they navigate and re-shape services in order to overcome barriers to attend to their child's health.

When Patricia found out about Dalia's diagnosis, she threw herself into researching the condition, the rights of people with disabilities, and different treatment and therapeutic options. For 7 years she has dedicated herself to advocating for Dalia and negotiating access to medical care, education, therapy and welfare on her behalf. In 2019, Patricia got a court order against her health insurance provider as they had consistently fallen short in covering the care Dalia needed. Part of this order exempted her from paying the excess on Dalia's medical expenses. When Dalia was hospitalised for an infection, Patricia showed the documentation of this exemption to the staff, but they said it wouldn't be needed until Dalia was discharged. When that time came a few days later, Patricia was presented with a medical bill for her daughter. She tried to explain the mistake and show the documents again, but the staff would not listen to her. They insisted it was her error, and that she would have to pay. Patricia did not have the money to cover the excess, and on top of that, she knew that she was entitled to an exemption. She was holding the document in her hand! She phoned a friend who worked in an unrelated capacity in the mayor's office. Speaking loudly enough that the hospital staff could hear her, she made it clear that she was speaking to an official of the local government and asked her friend whether she should involve her lawyer. The friend left her office and came to the hospital, and arrived wearing her uniform, which included a shirt and bag with the official logo on them. Under threat of legal escalation and in the presence of someone that they believed to have more power and influence, the hospital staff agreed to check the documents, and the bill was reduced to zero.

The gendered devaluation and delegitimization of women's experiential knowledge, based on its association with maternity, emotion, and affect, is built in to the foundations of biomedicine (Lay, 2000). Weingast (2016) shows how parental *autoatención* unsettles the idea that care and attention are separate spheres carried out by distinct actors (mothers care, doctors attend) operating in distinct spaces (care is domestic, attention is professional). In doing so, she unsettles the

ideas that facilities are exclusive sites of expertise and knowledge, and highlights agency of patients and carers. In Patricia's story, the role of experiential knowledge in bringing together official and unofficial channels is evident. Patricia had already gone through a long legal proceeding to get the exemption. This time she was looking for an expedient solution to a situation that she knew could quickly be resolved if she could get the staff to take her seriously. She realised that if she could not convince them to look at the document, then she would be over-ruled, and end up paying. She used her knowledge of the legal system, the threat of further legal action and the presence of an apparently influential figure to convince the staff member to look at the documents and correct their mistake.

Daniela migrated to Colombia from Venezuela in search of better access to health services for her son Eduard, who has CZS. At a group discussion she was explaining to another mother, Rita, about her recent experience seeking their permission to remain in the country. Without this document they were unable to enrol in a health insurance scheme, and had to choose between paying out of pocket or going without care. Daniela worked as an aesthetician, but she couldn't dedicate many hours to her work as she was caring for Eduard and Sergio. Her husband Andres was a street vendor, working long hours and earning less than the minimum wage. Their financial resources were very limited, and Eduard's health needs were extensive. Eduard needed nappies, medication, and an appointment with the gastroenterologist. He also has hip dysplasia which was causing him a lot of pain and putting him at constant risk of dislocation. The treatment for this would be a costly operation. Their situation was getting desperate, and Daniela explained to Rita that she had been to the migration and health offices several times trying to get the process expedited or find another solution. She told us that she kept getting passed from office to office, but no one would help them, they just fobbed her of or told her to wait a bit longer. Rita was always quick to get fired up on behalf of the other mothers, and frequently advocated on their children's behalf as well as that of her own daughter. She said that she would go with Daniela herself. She said that the way you speak to the officials influences how they treat you – "you can't go in and just ask them, or say, "oh I think I need this and that…" you have to go in and show that you already know your rights, you know what you need, and you're there

to get it." Rita had learned from experience that sometimes mothers needed to adopt a particular affect in order to leverage access to care. Letting professionals know that they are well-informed about their rights and the services available was a key part of getting professionals to take them seriously. Taking an advocate with them could help the caregiver to keep their resolve and show that they meant business. Rita's advice demonstrates that mother-carers behaviours and decisions are central to determining health outcomes.

Patricia shared a similar story about the advice she had given to family member of hers who had a disabled child. "I talked to her, and I taught her. I said, "you've got to go [to the clinic] because you got the referral to the nutritionist last year and they still haven't given you the appointment"." She gave the relative specific advice on what to say: "you're going to go and you're going to say this, this and this", and even how to speak, telling her: "You're not going to speak like this: [meekly] "it's no problem, just give me the referral…" No, you're not going to say it like that. You're going to say "I've come for my referral to the nutritionist. Oh, you won't give it to me? Okay, well then give me your information because I am going to make a complaint". She further explained why she had given the relative this specific advice: "I told her, you have to talk like this. You have to talk like this because if you don't, they'll say "come back tomorrow". And if you do that, they'll say it again the next day. So, you have to say, "I'm not going anywhere until this is sorted". Because you see, this is not the first time she's been to try and sort it out. *Entonces, tienen una mamadera de gallo* [frankly, it's a joke], they send you back and forth and back again." Rita, Patricia, and the other mother-carers have learned from experience that the manner in which they speak can be just as important as what they say. A few weeks after her conversation with Rita, Daniela messaged me to let me know that she had managed to get the permission to remain for her whole family. She told me she went to the office and was assertive, and said she wasn't leaving until someone helped her, and she left with the papers. Speaking to Rita had helped to strengthen her resolve to get the documentation expedited, and had given her a new approach to try out. By sharing their experiences and advice, mother-carers hope to help others effectively leverage access to care and resources for their children.

In this way, *autoatención* operates at the community level as well as within individual family units; mothers draw on their network to develop new strategies to negotiate access, and networks come together to provide advice, help to develop one another's cultural health capital, and contribute to the management of their children's' health and wellbeing. The collective self-management of health is one factor that sets *autoatención* apart from individualised conceptualisations of self-care. Most of the mothers I interviewed are in at least one local WhatsApp group made up of other carers and parents of people with disabilities. When mothers run out of medications or other supplies, they turn to these groups to see if anyone has spares. They analyse their options and recognise that waiting for a new prescription through the official channels may be too slow and could leave their child at risk of serious health complications. Based on this, the network of carers is the most appropriate resource they can draw on in that moment, as the administrative burden is low, and response times can be almost instant. They use their lay knowledge of specific medications, doses, and conditions to describe what they need and evaluate offers of help. This is not a replacement for seeking a new prescription, but it can help bridge gaps left by the formal health care system.

As Menéndez (2003) highlights, seeking care informally does not necessarily mean rejecting biomedicine, but rather assessing the available options and deciding on a course of action to promote of achieve health, which may include biomedical intervention. While patients and carers accept biomedical intervention as part of the self-management of their health, they reject the individualising biomedical model of health.

These experiences show that in the Latin American context, mother-carers self-manage their child's health needs by bringing different spaces and resources into contact with one another. The distinction between the different forms of cultural health capital that they utilise within and outside of formal systems is not very defined. Mothers' knowledge base is broad enough to cover a multitude of systems and spaces, and help them navigate within and between them; threatening legal escalation often gets the job done, though mothers know they have the knowledge and wherewithal to back it up if they need to. Informal sites of health care can act as

stopgaps when official systems are too slow or burdensome to respond to an immediate need. As they move between spaces and interact with different actors, mothers modify their affect, style of communication and how they carry themselves in order to leverage care. Their cultural health capital, which they have developed over a course of years since their children were born, enables them to (at least partially) integrate these different spaces together. They are active agents in the struggle for rights and services, and they deploy their hybrid health capital in order to safeguard their child's health in the absence of a more comprehensive safety net.

Sources of self-efficacy

I developed the latter part of this chapter based on a question I was asked after presenting an early version of my analysis of mothers' responses to health system barriers and cultural health capital. The question was whether I had a sense of how these mothers had developed the self-efficacy to act in the ways I had described. I shared some thoughts at the time, explaining that I believed their approach had been influenced by their enrolment in the cohort study, specifically their participation in a community of mother-carers and brigade visits. The question prompted me to return to the data and theory to explore this in more depth. I found theories of epistemic justice and the politics of recognition to be particularly resonant. The product of the exploration makes up the next section of this chapter.

All of the mothers in this research are enrolled in a cohort study (VEZ) (Mercado-Reyes *et al.*, 2021). An interdisciplinary brigade of health care professionals has visited their city twice a year for the past 7 years to examine the children, evaluate their development, and collect data for the cohort study. I was able to attend two such brigade visits, one in my field site of Barranquilla and the other in Neiva, the capital of Huila department. My discussion here will focus on the mothers' involvement in the cohort study, which in practical terms means her attendance at the twice-annual visits. These visits consist of consultations with the different specialists, in which the staff evaluate the child's development through clinical examination and asking questions to the parent.

In my observations of these visits, I was struck by the nature of the epistemic exchange that was taking place between parents and staff. Staff were reliant on mother-carers experiential knowledge in order to develop a full understanding of CZS. They were also interested in understanding the context that the families were living in, so that they could give tailored recommendations rather than generic advice. Considering the brigade visits as a site of epistemic exchange, together with the questions of self-efficacy and *autoatención*, prompted me to analyse these interactions from the perspective of epistemic (in)justice.

Epistemic (in)justice

Fricker (2007a) defines epistemic injustice as "a wrong done to someone specifically in their capacity as a knower" (p. 1). A feminist epistemology highlights the crucial role of social identity and marginalisation in the production of knowledge (Agra, 2020). Fricker (2007a) identifies two specific types of epistemic injustice in which an individual or community's social position are particularly implicated: testimonial injustice and hermeneutical injustice. Following Bhakuni and Abimbola (2021), I will use the more accessible term 'interpretative injustice' in place of 'hermeneutical injustice'. Testimonial injustice occurs when a speaker is assigned less credibility based on prejudice towards the speaker's social position or identity (Fricker, 2007a). Interpretative injustice arises from the prejudicial distribution of legitimised "sensemaking resources" (Bhakuni and Abimbola, 2021, p. 1). The mother-carers I observed in this research were generally younger, less educated, and from lower socio-economic strata than the clinicians and therapists that attended to their children. Several of the women in this research were also ethnically Afro-Colombian, or Venezuelan migrants. As a result, they are at risk of both testimonial and interpretative injustices in clinical and therapeutic settings on the basis of their social positions.

In terms of testimonial injustice, prejudice on the basis of age, education, socio-economic status, race, ethnicity, and nationality, combined with the epistemic privilege afforded to clinicians and therapists based on their professional training, could contribute to an "identity-prejudicial credibility deficit" for mother-carers in

clinical settings (Fricker, 2007a, p. 4; Blease, Carel and Geraghty, 2017). In addition, due to their close relationship with their child and the affective dimensions of the care work that they perform every day, there is a risk that mothers may be assigned less credibility due to their emotional connection to the subject matter. Based on this, clinicians may characterise mother-carers as lacking rationality or objectivity in relation to knowledge about CZS (Carel and Kidd, 2014).

During my fieldwork, I accompanied participants to medical appointments where the doctor established themself as the sole authority and engaged in a one-sided transfer of information. They showed little curiosity towards the practicalities of raising a child with CZS, and did not engage the mothers in dialogue about how best to meet their child's health needs. As a result, they sometimes gave advice and made recommendations that were unrealistic based on the family's circumstances, or conflict with the recommendations of other professionals. For example, when I attended the paediatrician with Rita, the doctor noted that some of the foods Rita reported feeding to Lola were excessively high in calories and recommended that she limit how much of those Lola consumed. The paediatrician showed little curiosity about why Rita was feeding Lola the diet she had outlined. If she had engaged Rita in a dialogue about Lola's nutrition, appetite, and feeding, she would have known that Lola doesn't have much of an appetite, and that several nutritionists have told Rita to make sure that Lola's food is sufficiently calorie dense so that a smaller portion can provide adequate nutrition. Within the same appointment, the paediatrician remarked that Lola was underweight for her age and height. She did not invite Rita to comment on this, and Rita said nothing. In this exchange, the paediatrician did not consider Rita to be a credible source of information about Lola's nutrition and feeding, and this perceived credibility deficit led her to give contradictory information that did not serve Rita in promoting her daughter's wellbeing.

Patients often experience interpretative marginalisation in healthcare settings (Carel and Kidd, 2014; Buchman, Ho and Goldberg, 2017). In the case of children with CZS, mother-carers engage with health care professionals on behalf of their children. Mother-carers and their children's medical providers lack shared

interpretative frames relating to the implementation of recommendations relating to their children's care. Rita explained to me that Lola had always sucked her thumb and fingers, and pointed out a hard callous on the side of her thumb that had developed over years of Lola sucking and chewing on the skin. Rita tried to stop her, but the moment her back was turned Lola would put her hand back in her mouth, and she sucked on her fingers in her sleep as well. Lola ate some solid food, which Rita cut up into small pieces for her. However, she didn't have much of an appetite, so Rita supplemented her diet with a fortified milk drink which she fed Lola from a bottle. Lola was born with a pronounced overbite, and sucking on her hands and the teat of the bottle had caused her front teeth to stick out. She continued: "so, what happens? As her teeth continue to grow, they come further forward. This makes it difficult for her to suck on her bottle, it's hard for her, the teat doesn't fit well in her mouth, so we spill more than she drinks, you see? Another thing, when she is drinking her milk, she also gulps a lot of air. The milk is spilling, and it gets to the point where she feels full of air, and she doesn't want to eat more. Imagine that. Soon she will get her adult teeth, imagine where they will go. When her adult teeth come in, they might be even more pronounced. They may be larger and it's going to be harder to give her milk. So, I don't want to keep giving her the bottle, but the nutritionist said if I take her off the milk completely, she will lose even more weight. It's a complimentary food that she needs because she doesn't eat as much as she should. Meanwhile the paediatric orthodontist wants her off the bottle because it is going to continue damaging her teeth." Rita was trying to find an acceptable balance between Lola's long-term habit of sucking on her fingers, the formation of her jaw, her appetite, their reliance on the supplementary drink, and the health of her teeth. The advice of the nutritionist and orthodontist were in conflict and each respectively ignored a number of factors at play. Each specialist was attempting to treat the patient in relation to their own specialism, leaving Rita to navigate the reality on her own. Mothers' ability to act on clinical recommendations is constrained by overlapping structural vulnerabilities that limit their time, money, and energy, in addition to the complexity of their child's impairment(s). Doctors may see their own advice as being straightforwardly translated into better health outcomes, but mothers have to fit them into a complex web of overlapping

circumstances and try to balance existing priorities and demands with the implementation of advice. The mother-carer is the point of articulation between different specialisms and interventions, and must bring them into contact and analyse them in the context of her own circumstances in order to determine a course of action (Menéndez, 2018). The lack of a shared interpretative frame between mother-carers and medical professionals leaves mothers frustrated with conflicting advice and precludes their recognition as epistemic agents in healthcare settings.

The politics of recognition

(Mis)recognition, as articulated by Honneth (1996), has been identified as a key factor in the production of epistemic (in)justices (Giladi, 2018; Medina, 2018). Conflict arises when the subjectivity and particularity of an individual or community is misrecognised or goes unrecognised (Giladi, 2018). Within healthcare settings, constraints on patients' agency to act in their own best interest regarding health and wellbeing may be misrecognised, leading to their behaviours being misinterpreted or discredited (Fisher, 2008). In the case of parents of disabled children, their behaviour may be misinterpreted as either too passive or overly assertive by service providers (Colker, 2015). On the other hand, positive recognition of one's strengths "by fellow members of one's individual community or by other communities of value" contributes to the development of self-esteem (Giladi, 2018, p. 145).

Mother-carers of children with CZS recognise that parents of disabled children strive to promote their children's best interests, but that their efforts may be constrained by limited time, money and energy. Unlike some medical specialists, mother-carers didn't tend to give each other generic advice. They explained how they would first assess another person's situation so that they could try to tailor their advice. Patricia told me about a family she met when she was visiting her mother in another department. In this family there were three disabled children, all aged in their teens, who had very few supports in place. Patricia said, "even though it's a different department, I still tried to help assess the situation and started giving advice. All I can do is try to help people figure out what's the first step: how can we

open doors". Rather than judging or admonishing the family for the lack of support their children were receiving, Patricia recognised that there were likely a number of factors influencing this family's pursuit of care for their children that were unknown to her. She recognised that she needed more information to inform the kind of recommendations she made to the family, and engaged them in a dialogue in order to learn more about their circumstances. She afforded the family credibility in accounting their own experiences and assessing their circumstances. Based on her experience raising Dalia and her knowledge of the context in which her mother lived, she was able to offer resonant interpretative frames through which the family could begin to assess their children's unmet needs and identify potential solutions.

The staff who make up the INS cohort study brigade have a long-term relationship with the families, and have come to understand that mothers operate within constraints. For example, mother-carers do most of the cooking and take responsibility for feeding the children. If food is not provided at an event, they don't stay long. Rather than interpreting this as a lack of interest (which would be a misrecognition of the situation), the brigade staff recognise their true motivation and how it relates to the circumstances of their daily lives, and take measures to lessen the burden and increase the possibility of participation. Providing lunch at the brigade visits reduces the financial cost of attending, and also alleviates the need for the mother to rush home and cook lunch for the family.

Further to this, I observed brigade staff phoning mothers on the day of their scheduled appointment to make sure they were planning to come and whether they had encountered any difficulty in getting there. Such behaviours reflect the staff members' recognition of the mother-carers rationality – mothers have good reasons for occasionally arriving late (such as experiencing difficulty securing transport to the clinic), or not attending (child illness was a common reason for rescheduling their appointment). The staff recognise that mother-carers are not unreliable or uncommitted but encounter obstacles and may lack the necessary resources to overcome them.

Staff members expressed their gratitude to the mothers for attending the brigade visit. In doing so, they demonstrated their respect for the mother's time and

recognition that she is busy and frequently under stress. Brigade staff also demonstrated their recognition of the balancing act that mothers engage in, as they try to promote their child's holistic wellbeing while constrained by structural vulnerabilities and juggling other priorities.

This attitude is reflected in the way that the brigade staff gave advice to mothers. Dr Blanca suggested to Patricia that Dalia start to sleep alone to develop more independence. Patricia explained that they don't have the space for that right now – the nurse sleeps with Dalia in the room she shares with her brother. Dr Blanca said, "I understand, it's something for you to think about in the future as Dalia gets bigger". Dr Blanca engaged Patricia in a dialogue about Dalia's sleeping arrangements. While Dr Blanca's primary interest is in promoting Dalia's development, her response demonstrates her appreciation that Patricia knows her own living situation best, that family circumstances are dynamic and can change over time, and that Patricia is best placed to assess and implement changes to Dalia's care. In a consultation with another mother, Dr Blanca made some recommendations about the child's education – at the time, he was not enrolled in school or receiving any at home tuition. The doctor followed her recommendations by saying "I know you already do a lot for him". By contextualising her recommendations in this way, Dr Blanca demonstrated her recognition of the mother's efforts and the existing demands on her energy.

Epistemic resistance

Epistemic resistance refers to acts of 'epistemic virtue' (Fricker, 2007b) by privileged groups (Agra, 2020). Reflexive "self-estrangement", on the part of the epistemically privileged is essential to enable 'virtuous listening' (Fricker, 2007b; Medina, 2013a, p. 19). Those in privileged positions must interrogate the role of their positionality in relation to their interlocuter in shaping epistemic exchanges (Fricker, 2007b; Medina, 2013a). Such reflexive self-examination creates the potential for privileged epistemic agents to use their "epistemic resources and abilities to undermine and change oppressive normative structures" (Medina, 2013a, p. 4). I observed the brigade staff engaging in acts of epistemic virtue demonstrating their openness to

knowledge that originates from other sources and perspectives through virtuous listening and self-estrangement.

The brigade staff are involved in research, so they have an explicit, epistemic objective. Their objective of producing knowledge about CZS promotes epistemic openness in interactions with mother-carers. Despite their privileged social position in relation to the mothers (they are more educated and belong to a higher social strata than the mother-carers, and mostly originate from major cities), epistemic openness allows the brigade staff to recognise that mother-carers have an "epistemic privilege" in relation to knowledge about CZS, since they have the opportunity to build up extensive experiential knowledge of the condition through care work (Blease, Carel and Geraghty, 2017, p. 4). As a result, they adopt a reflexive approach to the production of knowledge about CZS in order to make use of this experiential knowledge. During the brigade visit to Barranquilla, the staff reminded me that they "only got to see the children once or twice a year" and explained that they relied a lot on their mothers to attend and contribute to the evaluation for the cohort study. Rather than positioning themselves as experts, the staff engage mother-carers in a dialogue, 'pooling their epistemic resources' in order to generate new knowledge together (Medina, 2013b). The commitment to an epistemic objective has primed the brigade staff to engage in virtuous listening, which has had the effect of "neutralize the impact of identity prejudice on one's credibility judgement" (Agra, 2020, p. 40).

As Dr Blanca examined Dalia, she explained everything she was doing to Patricia in a relaxed voice. Her explanation was engaging, and Patricia frequently added further information. Dr Blanca talked about the importance of a good night's sleep, telling us "Dalia needs plenty of sleep because that's when she is resting her brain". Patricia said, "yes, and she sleeps better when it is cool at night. She naps in the afternoon from around 14:30-17:00, then sleeps 6-8 hours at night". Dr Blanca nodded and said, "very good, that is very good" as she continued to examine Dalia. Dr Blanca wasn't explaining anything that Patricia didn't know, rather by talking aloud during the consultation she was offering an opportunity for Patricia to contribute to the conversation. By creating an open dialogue, Dr Blanca allowed

Patricia the space to contribute more details about Dalia's sleep pattern, enriching the data that she was collecting for her research.

Epistemic interaction

The brigade visits have created a space for "free and equal epistemic interaction among heterogenous groups" in which "resources are pooled and experiences and imaginations are shared, compared, and contrasted" (Medina, 2013b, p. 8). Mothers have derived self-esteem in relation to their knowledge of CZS from recognition by other mothers and brigade staff. As a group, they are self-empowered by their participation in an epistemic community of mother-carers, and this places them on a sufficiently equal footing to the brigade staff.

Mothers were free to challenge medical knowledge by bringing their own experiential knowledge in the discussion. Dr Blanca asked Rita about Lola's sleeping patterns. Rita replied that she sleeps for at least hours per night "as long as I sleep with her and hold her". Dr Blanca looked concerned and asked Rita if she was getting enough sleep based on that arrangement. She also started to reassure her that it might also be good for Lola to sleep on her own too. Rita elaborated "if I don't hold her, she doesn't sleep, I don't sleep, and the neighbours don't sleep either. But she sleeps well as long as I stay with her". While Dr Blanca had her reservations about Rita and Lola sleeping together, she did not admonish or tell her that what she was doing was wrong. Rather, she inquired after Rita's own wellbeing, which gave Rita an opportunity to explain her reasoning. Promoting Lola's independence is a worthy goal, but Rita has to weigh up the importance of herself and Lola both getting a good night's sleep so that they are sufficiently well rested to face the day.

Mothers recognise the value of putting their experiential knowledge into dialogue with medical expertise. Patricia told me that Dalia's gastroenterologist gave her a diet to follow when feeding her, which essentially consisted of a list of foods Dalia could not eat. Patricia talked me through each item on the list and explained to me that now Dalia eats pretty much all of it, and that she had received support from their nutritionist to diversify Dalia's diet. I asked her if the gastroenterologist and

nutritionists talked to one another, she said kind of, but she still has to update them on what the other has said. In her experience, “the gastroenterologist is rigid” in their approach, so Patricia told me she prefers to explain to the nutritionist what Dalia actually eats. Speaking of the different medical professionals involved in Dalia’s diet and feeding, Patricia said: “They know a lot, but we, who spend every day with them, know more”. With this statement, Patricia highlights her detailed experiential knowledge of CZS and her daughter’s health, routines, and diet, and privileges this above the more detached medical knowledge of the specialists.

At the brigade encounters, both parties bring expertise and interest in the topic of CZS. The staff bring clinical expertise, research skills, and scientific understanding, and mothers bring experiential knowledge based in long-term observation and analysis of their child’s condition, behaviours, abilities, health, and the wider circumstances of their family life. Both parties bring curiosity and a desire to better understand CZS, whether it is professional/ academic or personal. Through mutual respect for the different forms of knowledge that each party brings, mothers and brigade staff are able to work together to co-construct knowledge about the still novel and relatively unknown condition of CZS. Doctors and nurses engage mothers in a dialogue, gathering more information about the child and the family in non-judgemental ways and responding with genuine interest. In return, mothers ask questions of doctors; offer corrections or add detail to what the doctor has said; speak candidly about challenges they face and worries they have about the child’s condition. Doctors make specific recommendations that take into account the specific circumstances of each family, and frame their recommendations within the wider context.

The brigade staff allow for 'particularity' – they recognise the particularity of each family is unique in terms of their experiences, capabilities, and structural vulnerabilities. They recognise mothers as experts in terms of knowledge, having the privilege of experiential knowledge and deep engagement with their child and CZS, and simultaneously constrained materially in terms of money and time in their ability to follow prescriptions and advice. If medical providers fail to recognise

mothers as epistemic agents in discussions of CZS, they risk misrecognising their actions and motivations, and causing epistemic harm.

"This is for life"

Over a course of years, the brigade staff have developed a strong relationship with the mother-carers which has facilitated the development of the epistemic community around CZS. However, while they engage as epistemic equals, the motivations of the mother-carers and staff for participating in the cohort study differ. For the brigade staff, the purpose of the cohort study is clinical research. Ana put it in simple terms: "The idea of the brigades was primarily to conduct the medical evaluation and see how the children were". Andrea made it clear that she understood that the brigade staff had a purpose for their visits when she said, "The brigade are doing research. If not for that interest, they would leave." Both the researchers and the mother-carers acknowledge that for the researchers, the production of knowledge on CZS is the primary purpose of the cohort study and brigade visits. Mother-carers have diverse motivations for their continued engagement in the cohort study. For one, participating in the study is a way to access specialist appointments. Some of the families had experienced periods without health insurance cover, and attention from the brigade was the only free medical care they got for their child in those times. This is one way that mothers self-manage their child's care in the face of limited access to health services due to a lack of insurance cover for specialist care. There are also indirect benefits of participating in the cohort study. Through their discussions with the brigade staff, mother-carers develop their cultural health capital, which enables them to more effectively engage in *autoatención* on their child's behalf. They learn the technical terms and how to deploy them in conversations with other healthcare professionals. Attending the brigade visits also offers an opportunity to seek a second opinion on advice they have received from their child's paediatrician or other specialists they have seen, again demonstrating the key role they play in managing their child's condition.

Even though they have established an equitable epistemic relationship, materially the power still lies with the cohort study staff. They determine when the visits will happen, and ultimately have less at stake than the mother-carers. Nonetheless, participating in the cohort has conferred benefits to the families, and the brigade staff have done what they can to level the playing field where possible. As I have already demonstrated, mother-carers are highly self-sufficient. Just as they bring together routinely available formal and informal health services, they have reconstituted the brigade visits to serve their child's health needs. They have used the time, space and presence of other mother-carers to form an epistemic community through which they can enhance their cultural health capital in order to engage in more effective practices of *autoatención*. Andrea explained the difference in stakes for mother-carers "This does not end until they are no longer with us. This is for life. Their medical treatment is lifelong. And as far as we are concerned, we are responsible also for life." In contrast to the clinical staff of the brigade, who she believes "would leave" if not for their academic interest in CZS, Andrea highlights that mother-carers involvement in CZS and learning about how best to manage the condition will be life-long.

Epistemic community of mother-carers

As Agra notes, in order to overcome epistemic injustices, "the minority group must be self-empowered so they may interact with the dominant group at a more equal footing" (2020, p. 46). Together with the assertion that "it is communities, and not individuals, which must be recognized as epistemic agents" I address the mother-carers self-empowerment by analysing the epistemic community that formed among them as a result of their long-term involvement with the cohort study (Nelson, 1993, cited in Agra 2020).

The twice-yearly brigade visits to collect data for the cohort study have created spaces for mother-carers of children with CZS to meet others in a similar position to themselves. The consultation rooms are adjacent to a large gymnasium which is usually used for physiotherapy. Lunch is provided at the brigade visits, and the gym is used as a waiting area and dining room. Providing a meal and somewhere to sit

promotes social interaction between the mothers, which is an important source of emotional and informational support. In the introduction to her book, Leontiou reflects on her experiences raising a son with multiple impairments. She writes: "when I reflect on the good interventions that I have brought to my son, most have been recommendations from other mothers. Doctors don't offer many ideas for navigating the world of disability" (Leontiou, 2010, p. 2). In this reflection, Leontiou captures something essential about the different interpretative frames available to doctors and mother-carers. "Navigating the world of disability" implies a holistic journey through complexity, in which one must manage conflicting priorities and manage uncertainty. Mother-carers, speaking from a place of shared experience, are well situated to offer advice and guidance.

Ana, one of the paediatricians in the INS brigade, explained the process she had observed over the first few years of the cohort study. She told me that the brigade was made up of various specialists who evaluated each child's development and health. "Within the context of these brigades, the families started to get to know each other. Because, well, at that time they felt very alone, the condition was not well recognised, there was no program in the city to bring together families affected by Zika, so it came about organically instead. The idea of the brigades was principally the medical evaluation and check-up of the children, but of course, as there were long waits, that is, families might be there all day waiting to do the eyes, the ears… Anyway, they started to interact, to get to know each other, to share the problems they were facing with their child, you know? So, it seemed to us that they started to realise that fortunately they were not alone, even though they faced a serious challenge with their child's health, and that caused a great deal of stress because at that time no one could give them many answers about the condition. They met with other families, they saw that those families had children like theirs, that they faced similar struggles, that they had a lot in common. Well from there they began to form the bonds of friendship; they began to make friends between themselves". Ana explained that the mothers created a WhatsApp group to stay in touch between brigade visits. Through that group chat, she said, "they were also filling the gaps they found in the health system, sharing "tips" if you like. Something like, "how did you get your child's surgery authorized?" "listen, this is

what I said..." This has helped them as they could learn from each other's experiences… This social group they have helps each other in many small ways, which adds up to a lot."

Early in the Zika epidemic, there were no experts on Congenital Zika Syndrome, so when mother-carers sought information about the condition, "no one could give them many answers". In the absence of reliable information about CZS from external sources, mother-carers came together to form a supportive epistemic community. They shared facts they had learned, discussed strategies for accessing care and began to "fill the gaps" in official knowledge that were already emerging. Experiential knowledge about children with CZS and their care shared by more experienced mother-carers was a valuable, and valued, epistemic resource within this community. The recognition provided by this epistemic community has been a source of self-empowerment for mother-carers.

Mothers noted that they had less social contact with each other during the pandemic due to the reduced frequency of brigade visits. I asked Hilaria about the impact of the reduced frequency of brigade visits in the context of COVID-19.

Ros: You told me before about some of the ways the pandemic affected you, for example that the brigade did not visit as often during that time… What impact did that have on you? The lack of opportunities to meet with the brigade and the other mothers?

Hilaria: Well, at least when we went there [to the brigade visits] we would talk among ourselves. One would be talking to another; others would be talking over there. And in that way, one would learn from another. We all talked, and we all communicated with each other. It was better in that way because, look, for me, if I go and sit out there [gesturing to the street] and talk to a neighbour who has a typical child, it's not the same".

Later in our conversation, Hilaria elaborated: "It was more than just a conversation of saying "oh, right, sure". [It was more like]: "No, look, this is what I did. When my child was her age this is what I did." It's like we learned… we learned from ourselves, that is, from experience, what things to do." By highlighting the fact that

conversations with parents of non-disabled children are "not the same", Hilaria's statement illuminates the importance of "having one's traits and accomplishments positively recognized… by fellow members of one's individual community" in developing individual self-esteem (Giladi, 2018, p. 145). In her statement that "we learned from ourselves", Hilaria points to the epistemic self-empowerment that the mother-carers have derived from their participation in a supportive epistemic community.

Concluding remarks

Mother-carers navigate health systems on behalf of their child. Barriers, delays and denials to accessing care have become routine, and they have developed strategies to overcome them and gain access to care. Bringing together *autoatención* with cultural health capital from a feminist perspective highlights how mother-carers enact agency in the face of structural vulnerability and health system barriers. By synthesising these two theories, I have shown how mothers use diverse cultural resources to bring together and reconstitute formal and informal healthcare resources and services in order to self-manage their child's health. An analysis of mother-carers navigation of formal and informal healthcare spaces from the perspective of *autoatención* demonstrates that patients and carers are the nucleus of the health-care-treatment process.

Recognition of mother-carers agency and responses to barriers invites discussion of mothers as epistemic agents and their participation in communities concerned with creating new knowledge about CZS. In their routine interactions with healthcare professionals, mother-carers experience epistemic injustices on the basis of their social position. The brigade staff have a specific epistemic objective and adopt a reflexive position towards knowledge production on CZS. They recognise the epistemic privilege mothers have in terms of the wealth of experiential knowledge they have developed about their child and the condition. Brigade staff resist reproducing epistemic harms, rather engaging the self-empowered mother-carers as partners in knowledge production. I have identified mother-carers participation in the INS cohort study as a source of self-efficacy that

promotes active engagement in practices of *autoatención* on behalf of their child. Recognition within the epistemic community of the brigade, from staff and other mother-carers, fosters self-esteem (on an individual level), which contributes to the self-empowerment of the community of mother carers ("we learned from ourselves"). However, while the brigade staff have a professional interest in CZS, mother-carers have a deeply personal investment in generating new knowledge about CZS and refining practices of *autoatención* on behalf of their children. To this end, they have used the space provided by the brigade visits to form an epistemic community.

The formation of an epistemic community of mother carers represents a disruption to the individualising biomedical model of health. Adopting a feminist perspective, I have shown how mother-carers engagement in practices of *autoatención* troubles the idea that professionals exclusively hold expertise about health matters. My analysis, synthesising *autoatención* and cultural health capital, has re-focused attention on the importance of experiential knowledge on the individual and community level. The role of women's collective action will be explored further in chapter 7.

PART III: DISABILITY

Chapter 6: Social production of disability and debility

Introduction

In this chapter I will discuss two inter-connected topics: the social construction of disability, and the social production of impairment. As I have shown in Chapter 5, mother-carers experience barriers as they try to negotiate access to health services, therapeutic interventions, and education for their children. In line with the social model of disability, mother-carers identify external barriers as the cause of challenges they and their child face, rather than deficits inherent to the child. Due to the close relationship of care between them and their child, mothers experience these barriers as well, and as a result, they experience discrimination by association (UN CRPD, 2022). This finding invites us to go beyond the social model in order to understand how mother-carers take on the identity of a person with a disability (Greiner, 2022).

Further to this, mother-carers acquire impairment due to caring in the absence of suitable support. Discrimination and neglect can produce and worsen impairment for both the child and the mother-carers. The embodiment of neglect is conceptualised as debility (Puar, 2017a). Williamson, Engel and Fietz (2023) have shown that creating enabling environments for disabled people during the COVID-19 pandemic was mentally debilitating to caregivers. In this chapter I extend these findings, demonstrating that the absence of support can be both physically and mentally debilitating to both the mother-carer and child, even in the absence of any acute crisis.

Models of disability

Disability has been understood differently over time and in different contexts. Within disability studies, understandings of disability that have dominated (in the global north) at different times are referred to as 'models' of disability. I will outline

some of the most commonly discussed here and demonstrate how they apply to CZS in the literature and in my analysis.

Moral-religious model

The moral-religious model of disability has the longest history, and was the dominant model before the development of the scientific method and modern medicine (Retief and Letšosa, 2018). In this model, the presence or absence of disability is believed to be determined by an individual's moral standing (Retief and Letšosa, 2018). Disability may be understood as a punishment from God for the sins of the individual or their family, or a test of faith wherein an individual could be "cured" through prayer and belief in God (Retief and Letšosa, 2018). Those who are not "cured" were therefore considered even more sinful and lacking in faith, and thus the presence and persistence of a disability could lead to social exclusion for individuals and even entire families (Retief and Letšosa, 2018).

An understanding of disability based on the moral model appears in research about the Zika virus and CZS. In the beginning of the Zika epidemic, the relationship between the virus and congenital disability was poorly understood. In a climate of uncertainty and influenced by the moral model of disability, mothers suggested that their child's disability was a punishment from God for past transgressions, such as having an abortion, getting divorced or holding negative attitudes about people with disabilities (de Melo *et al.*, 2020; Laza-Vásquez, Cortés-Martínez and Cano-Rivillas, 2020). Stigmatising attitudes and discriminatory behaviours towards mother-carers and their children also appeared to rest on a logic of disability as a marker of moral failure; people avoided engaging with them and their child, believing that the mother was responsible for her child's condition (Freitas *et al.*, 2020; Laza-Vásquez *et al.*, 2020). In the case of CZS, disability discrimination grounded in moral understandings of disability are highly gendered. As raising children is culturally inscribed as the primary domain of the mother, punishment and blame are directed primarily towards female caregivers.

Mothers also found ways to cope through the possibility of moral redemption, believing that God had sent them a child with a disability to test them, to show that

they were capable of being especially good mothers or of rising to a great challenge (Laza-Vásquez *et al.*, 2020; Lima *et al.*, 2020; Tirado *et al.*, 2020). While religious narratives may offer personal comfort to disabled people and their carers, the moral model of disability ultimately reinforces harmful stereotypes about disabled people and offers little in the way of combatting discrimination and oppression.

I identified moral-religious understandings of disability in my research. Andrea told me that her faith had been tested as she could not accept that God would punish her son for her own faults. In an interview, she said: "Sometimes I ask myself, "why Maurice?" Do what you want with me, but why him? If he had something on his conscience, if there was a reason, if he was guilty of something… but he's not. To me it seems unjust that he's paying for mistakes that I have committed in the eyes of God. That's something I cannot accept." Maurice's condition causes him pain, he gets distressed if he is left alone or cannot hear people near him, and he has had to have several surgeries throughout his childhood. Andrea draws on a religious explanation for Maurice's condition, referring to God punishing her for past faults. Rather than accept this explanation however, she questions what the justification is for Maurice to suffer. While Andrea draws on a religious explanation for Maurice's CZS, she does not accept that she or her son deserve to be punished.

Medical model

With the development of the scientific method and the dawn of 'modern' medicine, came an interest in categorisation and quantification, which extended to bodies and behaviours (Llewellyn and Hogan, 2000). This led to the idea of average or 'normal' bodily structure and function and way of being, and anything outside of the 'normal range' came to be understood as deviant, 'abnormal' and inherently inferior (Smart, 2009). Within this model, disability is thus understood as a deficit within the individual, to be overcome through rehabilitation and the search for a cure (Llewellyn and Hogan, 2000; Smart, 2009).

Children with CZS and other disabilities are often measured against the expected physical, cognitive, and communicative abilities of a typical child their age in medical settings. I accompanied Rita and Lola for their first visit to a new

paediatrician, who carried out an exhaustive clinical assessment, consisting of a questionnaire and physical examination, and compared Lola's score to her chart. She assessed Lola as having the developmental age of a 6-month-old child, in contrast to her chronological age of 7 years. In previous meetings, Rita had told me about the different ways Lola had developed over time.

Rita: Before, if you said "Lola" it was as if she didn't hear you – to the point that they did a hearing examination to see if she was deaf.

Ros: She didn't react at all?

Rita: No, nothing at all – she didn't move her eyes or anything, it was as if you weren't there.

Ros: What age was she at that time?

Rita: This was when she was around three, three or four years old. So before, it was like that. Then it started, first with her father, when he said her name, she started to look towards him. She knew who was calling her and she would smile. Before, she didn't recognise her name. Now, she moves her head, looks over towards the person who is calling her. She knows the different voices, of her dad, my sister, and me. She knows who is who based on their voices.

Over the years, Lola had not only learned to recognise the voices of her family members, but has become more responsive to sound and light, and started trying to sit up and roll over. She had progressed a lot since she was a 6-month-old baby, but the doctor's assessment and charts didn't have room to see Lola's development as she progressed at her own speed. The medical model, with its focus on rehabilitation and cure, presumes a linear process in which individuals work towards overcoming their disability through treatments and therapy, finally arriving through a combination of perseverance and technical intervention, at a state of wellness and able-bodiedness (Fisher and Goodley, 2007). Such a model has little space for the lived realities of people with disabilities and their carers. Carers experience frustration and disillusionment at the disconnect between how their child's disability is treated by medical professionals and their lived reality (Fisher and Goodley, 2007; Williamson, 2018).

Mothers push back on the medicalisation of disability by emphasising the difference between disability and illness. Scott (2020) found that mothers of children with CZS understood disability as a social construction and related to a "bodily way of being in the world" (p. 20) rather than a biomedical state of sickness. Mothers in my research also emphasised this distinction. Patricia recounted a story about a woman she met on the bus one day: "I was sitting on the bus, and a woman was staring at us. She just couldn't resist, so asked me "oh dear, is the little girl sick?" I looked at her and I said "no, she doesn't have a cold, she doesn't have a fever, she doesn't have anything." Then she looked embarrassed!" Mothers reject the idea that there is something 'wrong' with their child, making the distinction between a disability and an illness clear to less informed people they meet.

Mothers also resist the medical model view that disability is a burden on the family. Children with complex and congenital impairments are often framed in the academic literature as a drain or burden on their caregivers, which reinforces an individualised, deficit based model of disability (Ryan and Runswick-Cole, 2008). In contrast, mothers in this research identified their child as a source of joy and peace in their lives. Towards the end of an interview, I asked Catalina if there was anything else she wanted to share about her family life and her experience raising Dominic. She thought for a moment and said, "Dominic brought a lot of love into our house when he arrived, and he makes us feel calm. He is a very peaceful boy; he inspires peace of mind. When I'm feeling hopeless, I go to him and hug him, and I feel that tranquillity... For me, Dominic brings me a lot of peace of mind". Hilaria shared a similar sentiment about Máximo's role in their family. "Well, he's been a blessing to our family. When we're sad, when we're grumpy, it's him who puts us in a good mood. He stops us from being sad… how can I put it? When he smiles". For both of these families, the child with CZS brings happiness into the home. Mothers do not identify their child's impairment as a source of stress or sadness.

There is overlap between the moral and medical model of disability. Public health messaging and news coverage of the Zika epidemic focused on individual preventative measures that women who were already pregnant or intending to become pregnant should take to avoid being infected with Zika. As with moral

narratives, individualised prevention messaging was targeted explicitly towards women, adding a gendered dimension. Public health agencies in Latin America and the Caribbean recommended using repellent, wearing long sleeves, and clearing the area around the home of standing water (Minsalud, 2015, 2016b, 2016e). Several ministries of health, including that of Colombia, also recommended that women avoid or delay pregnancy for the duration of the epidemic (Minsalud, 2016b). The focus on individual measures in the public health response to Zika obscured the underlying social causes of Zika infection and ultimately Congenital Zika Syndrome: lack of access to piped water and wastewater disposal, faltering vector control efforts, poor urban planning, and the high cost of repellent, among others (Ali *et al.*, 2017; Albuquerque *et al.*, 2019; Almeida, Cota and Rodrigues, 2020). This messaging fostered a narrative of individual responsibility, and research has since found that women who contracted Zika felt blamed and shamed for not being careful enough to effectively avoid becoming infected (Freitas *et al.*, 2020; Laza-Vásquez *et al.*, 2020). Individual responsibility for health and disability goes hand in hand with the attribution of ill health and disability to moral failure, and by embracing an individualistic approach to the public health issue posed by the Zika virus, ministries of health and other agencies have inadvertently helped to strengthen that association.

Social model

The social model of disability originated in the disabled peoples' movement and has been mainstreamed in research and policy. In the second half of the 20th century, grassroots organisations of disabled people began to come together to form a broad coalition for disability rights (Sabatello, 2013). They demanded rights and pushed for the inclusion of disabled people in decision making processes. Disability rights activist argued for a new understanding of disability and disabled people. They refer to the biological and physiological difference in form or function as impairment, and explain that people with certain impairments are *disabled* by oppressive social structures (Shakespeare, 2013). While the medical model locates the deficit within the individual, the social model posits that the deficit is in political, economic, and social structures that oppress and exclude people on the

basis of their impairment. The demands of the disability rights movement can be articulated through the social model of disability, which "mandates barrier removal, anti-discrimination legislation, independent living and other responses to social oppression" (Shakespeare, 2013, p. 216). From this perspective disability can be understood as an interaction between the biological, political, economic, and social. The disability rights movement and the articulation of the social model of disability brought about a massive shift in understandings of disability and the material rights of disabled people (Shakespeare, 2013). The International Classification of Functioning, Disability and Health and the Convention on the Rights of People with Disabilities both acknowledge the role of the environment and social context in the construction of disability, and call for an end to discrimination, enabling participation and independence, and inclusion for people with disabilities (WHO, 2001; UN General Assembly, 2006).

Within the literature on CZS, interpretations of disability grounded in the social model are apparent. Mother-carers identify external social and political barriers that make their lives difficult and limit their child's opportunities for inclusion and wellbeing. Long distances to clinics and the associated travel time; a lack of access to accessible, affordable, reliable transport; fragmented services, and lack of services were all identified as barriers to the full enjoyment of rights and health for families raising children with CZS (da Silva and Silva, 2020; de Melo *et al.*, 2020; Mendes *et al.*, 2020; De Sá and Pletsch, 2021). In many cases, the identification of external barriers led mother-carers to form social movements and demand better access to healthcare, therapeutic interventions, and education for their children (Diniz and Andrezzo, 2017; Ventura *et al.*, 2021).

Among the participants in this research, mother-carers primarily identified social oppression of disabled people as the source of their challenges, rather than an inherent problem of deficit within their child. In other words, their conceptualisation of disability largely aligned with the social model of disability. Several participants told me that public awareness of disability had increased, and attitudes had progressed during their lifetimes. In the first group discussion, they talked about how things used to be and compared it to the present. Catalina

explained that when she was younger, disabled people were rarely seen in public as families usually kept them at home. She said: “we can talk of inclusion now, because before people [with disabilities] were kept in the house all the time”. Daniela agreed that things had changed, commenting that friends and neighbours say hello to both of her sons when they go out together. Hilaria added, “sometimes as the mother you feel invisible because people say hi to them but not to you!”.

While friends and neighbours generally treated both mother and child with respect and kindness, families still received insensitive comments from strangers. In line with Patricia’s exchange with the woman on the bus, other mother-carers highlighted terms that they found offensive, such as *‘enfermito/a’* (sick little boy or girl), or terms that implied their child has a ‘problem’. Mothers attributed such encounters to a lack of experience meeting people with disabilities, and a lack of education about disability. Patricia described the combination of limited experience and lack of education as a “cultural failing”. She said, “there is a lack of awareness of disability. People don't understand that people with disabilities are people like us, with a different way of living”. In this statement, Patricia emphasises the similarity between people with and without disabilities, rather than the difference. She locates the point of difference in the way of living rather than within the person themselves, firmly situating the difference in the social world and rejecting the idea that people with disabilities are inferior or flawed. Patricia told me she didn’t know much about disability before she had Dalia, she had heard of Downs syndrome, but wasn’t aware of many other conditions. She has arrived at this understanding of disability through the experience of raising Dalia, researching her condition, fighting for access on her behalf, and engaging with other parents of children with disabilities.

Beyond social attitudes and common beliefs, mothers identified a lack of opportunities and support for children with complex disabilities to participate in everyday life. Andrea put it to me frankly; “This is the reality: for someone like Maurice there aren’t many opportunities. What opportunities are there for him? There’s no inclusion, so it’s complicated, there are no opportunities. There are other people with disabilities who have a wheelchair or another device to allow

them to walk, they have their jobs and professions. But for Maurice there is none of that." While, as Catalina points out, disabled children are afforded the bare minimum of participation in public life, opportunities for inclusion in all sectors of society beyond this are still very limited. Andrea identifies that in some cases, assistive technology can contribute to overcoming barriers. However, "Maurice has a wheelchair and pushchair but there's no space to use them in the apartment, and it's difficult with the stairs." The overlapping circumstances of living in a second story apartment in a low-income neighbourhood, and the complexity of Maurice's impairment means that the promise of assistive technology to remove barriers has not been realised in their case.

In addition to pushing back on ableist attitudes, mothers strive to promote their child's inclusion in everyday activities. When I asked about how Julia and her family spent their free time, she told me, "If someone in the family has a birthday party, they invite him (Stefano), and if we can make it, we go; most of the time we go. I try in every way I can to include him, to give him a normal upbringing, in spite of his disability, to give him the same childhood that any other child has." Promoting inclusion in family life has been more achievable than shifting broader structural barriers like access to education, and accessible transport.

These persistent structural barriers have wide ranging effects on disabled children and their caregivers. Rita elaborated on some of the barriers that prevented Lola from attending school. "They sent me the paperwork for her to start school next year. But anyway, that is a whole other process, because, well, a school for children with disabilities, which should be public and should be inexpensive, [in reality] they're very expensive. You pay the monthly fees so already its expensive. Then you have to get the transport, and someone has to go with her…" Rita continued, explaining that she had previously tried to enrol Lola in pre-school, but the school rejected her application. When I asked why, she told me: "it's because the staff aren't equipped to care for a child with a disability." I asked Rita whether schools in Colombia used an inclusive approach, with children with and without disabilities together in the same classes. She said it was unusual to see mixed classes, then elaborated further: "Well, it depends on the disability because if you had a child

with, oh I don't know, let's say they had polio and their legs are affected so they can't walk, but on a cognitive level, they're completely fine. Then, that child would be able to understand the classes and participate with the other children. So then, yes [you would see them in a mixed ability class]. Or a child who is missing a limb, then yes. But with cognitive disabilities, with cerebral palsy, let's say, no, you wouldn't see them in the same class. Because the teachers aren't trained. It is a commitment and a very big responsibility." The barriers to accessing education operate at different levels and intersect with socio-economic status and limited access to resources. Furthermore, it is children with cognitive disabilities and multiple or complex impairments that face the most barriers and greatest exclusion.

Lack of access to appropriate, reliable transport is not only a barrier to attending school, but also makes attending medical appointments and therapy more difficult. Public transport is largely inaccessible for mothers taking their children to appointments, as most buses do not have level boarding to allow pushchairs or wheelchairs to board. Patricia told me she used to try to take Dalia on the bus in her old wheelchair, but it wasn't easy. If a bus arrived that did not have an accessible entrance, they would have to wait for the next one to come, as she could not carry both Dalia and the chair up the steps on her own. They were often left waiting in the hot sun and arrived late to appointments due to the inaccessibility of the buses.

Taxis are a more accessible option as wheelchairs can be collapsed and stored in the car boot and mothers can take time to sit down with the child securely on their lap before the vehicle moves off. However, for the majority of the families, they are not affordable, especially for regular trips. Hilaria had a fall while carrying Máximo, and he fractured his femur. He had surgery and his leg was set in a cast while the bone healed. After that, Hilaria was afraid to take Máximo to appointments on the bus as she had previously, carrying him in her arms, in case of a jolt or another fall that could cause further injury. She told me, "We're going to get help to submit a tutela for transport services to be provided. To get to the clinic in a taxi it can be $15,000 COP [around £3] each way, and that's $30k that we don't have. Since Máximo's injury I can't use the bus with him as it's even more risky now and he could get hurt." Faced with the choice of an unaffordable taxi ride or unsafe bus

journey, Hilaria stopped taking Máximo for in-person therapy and made a request for at-home therapy instead while he recovered. The order was granted and approved quickly, but the service didn't begin for another two months. Hilaria said that she might try to add the therapy request to the tutela to avoid further delays. It was particularly important for Máximo to have regular therapy while he recovered from his broken bone to make sure it healed well and to restore muscle tone that was lost while his leg was in the cast.

Children with complex, cognitive impairments from low-income households face multiple overlapping barriers to full participation and exercise of their right to health and education. Mother-carers recognise that a lack of awareness of disability and discriminatory attitudes towards disabled people create physical, economic, and administrative barriers to accessing care and support for their child.

Mixing models

While mothers seldom compare their child to non-disabled children in terms of development, they do compare them to other disabled children. Mother-carers make comparisons between different diagnoses and impairments, highlighting how children with complex or multiple impairments experience the greatest level of exclusion. Catalina is the adoptive mother of four young boys, all of whom have an impairment or long-term condition. Among them is Dominic, who has CZS. Catalina explained that while two of her sons attended school, Dominic's condition was "quite severe" and for that reason he did not have any kind of educational provision. Julia shared a similar reflection on the stratification of exclusion. She was telling me about a school that Stefano had previously attended, and said that "for children with different diagnoses, Downs Syndrome for example, or autism, they have courses in bakery, arts... the teachers are very dedicated." However, there was less provision for children with complex disabilities produced by multiple physical and cognitive impairments. These discussions reflect a view of disability grounded in the social model, in which societal structures interact to exclude individuals with impairments.

Other discussions among the mother-carers in which they compared one child to another reflect an understanding of disability more aligned with the medical model. In a group discussion, Andrea said that she knew of other children affected by Zika who were "more functional", and that "each one is affected differently". Catalina said, "look at Liliana, she is active and energetic, she runs, crawls, and pulls herself up." Rita clarified that the extent of the child's symptoms depended at which point of gestation the mother was infected with the virus. She continued, "for example, Dalia is better than Lola, and Liliana is better still than Dalia". Rita uses the word 'better' here to mean 'more functional' in terms of coordination and cognition.

On one hand, placing the children within a hierarchy reflects a deficit-based understanding of disability. On the other hand, they have come to understand what is typical for children with CZS and other complex impairments, and their comparisons often highlight the similarities among their children in addition to the differences. Rita told me it was difficult for Lola to maintain a healthy weight as she did not want to eat. I asked "Is it that she doesn't have an appetite? That she is not interested in food?" and Rita replied "Yes, and the worst thing is that it's normal for them [children with CZS], so it's tricky…" In group discussions, the mother-carers discussed the age at which their children lost their milk teeth, their birthweights and bowel movements. These discussions were peppered with comments about the children's shared characteristics and what is typical at each age for a child with CZS. Such discussions are at least in part aligned with the medical model. Nonetheless, within the same set of exchanges, they reject the idea that there is one 'normal' way of being by redefining what is typical for children with CZS based on their knowledge and experience. This apparent contradiction demonstrates that a linear view of models of disability in which each one eclipses the next is overly simplistic; within one person and even one interaction, behaviours and attitudes can exist that reflect different ways of thinking about disability.

Overall, mainstream models of disability developed in the global north make for a useful starting point to analyse constructions of disability as they relate to CZS, but they are insufficient to capture the full experience of disabled children and their carers from low-income backgrounds, living in the Global South, facing multiple

intersecting forms of oppression. Speaking from a decolonial perspective, it is clear that "disability across cultures, contexts, spaces and places can be hardly encapsulated in all embracing static models, goals or strategies" (Grech, 2016, p. 16). Indeed, even within the UK context (where much of the scholarship on models of disability and the social model has been produced), "parents of disabled babies… consistently defy categorization." (Goodley, 2007, p. 146). Anthropologists can make useful contributions to disability studies as they bring a 'critical outsider' perspective that is less tied to mainstream models of disability (Staples and Mehrotra, 2016). This is what I aim to do in the rest of this chapter, through the synthesis of critical perspectives from the global north and south.

Going beyond the social model

The social model of disability formed the jumping off point for the majority of the critical approaches that came afterwards. Critiques of the social model have formed the basis for the development of critical perspectives, which are more apt to explain the experiences of families raising children with complex disabilities under conditions of poverty, neoliberalism, familism and ableism in the global south.

Disability as a way of being

Within the social model, disability is conceptualised as an interaction between an individual's impairment and their environment. Impairment has become naturalised as a lack or difference in bodily form or function, which implicitly relies on the idea that there is a 'normal' way of being (Goodley and Swartz, 2016; Araneda-Urrutia and Infante, 2020). A more critical approach situates impairment as part of natural human diversity (Terzi, 2009). Patricia explained that "people don't understand that people with disabilities are people like us, with a different way of living". In this statement, Patricia emphasises the similarity between people with and without disabilities, rather than the difference. She rejects the notion of a hierarchy between people with impairments and those without, and locates the point of difference in the way of living rather than within the person themselves. With this, she not only situates the difference in the social world, in line with the social model,

but goes beyond this, rejecting the idea that people with impairments are inferior or flawed.

Pain as a harm

The social model identifies social barriers that are disabling to people with impairments as the source of exclusion and thus the location of the harm of disability (Shakespeare and Watson, 2001). However, Barnes (2009) points out that some embodied 'harms' of impairment, such as chronic pain, cannot be resolved by the removal of societal barriers.

Mother-carers also identify pain as a harm of CZS. The impairment is not a deficit with the child, but their pain does detract from their quality of life in a material way. They highlight the aspects of their child's impairment that cause them pain and discomfort. Hilaria explained how she sees things: "Well, we're happy with him how he is. No, no – we wouldn't have wanted to see him in this condition. But he's been a blessing to us." Máximo had surgery on his hip when he was five years old and needs another surgery as his hip dysplasia causes him pain, making him irritable and stopping him from sleeping. Hilaria identifies pain and discomfort as harms of his impairment. Andrea also struggles to accept Maurice's pain and suffering. She separates this from her acceptance of her role in caring for him and working to break down barriers and gain access to services on his behalf. "Look, I still can't accept his condition, in the sense of why it happened to him. In terms of dealing with his condition, of what I have to do for him, yes, I have accepted it. When I say I can't accept his condition, what I mean is, why did this happen to Maurice? Why Maurice? Just to make that clear." Andrea's anguish stems from her inability to alleviate the pain that Maurice endures due to his condition. Pain and discomfort are unquestionable harms of CZS.

Independence

The idea of striving for independence marginalises the experiences of those with complex and cognitive disabilities, for whom the type of independence that the social model prioritises may not be possible or desirable (Valim, 2020). Policies that

focus on economic independence for disabled people rely on capitalist logic that assigns value to individuals based on their productivity (Ferrari, 2020; Parra, 2020).

Mother-carers believe that their children are unlikely to become independent, even with the aid of technology and the removal of societal barriers. Andrea and I discussed her studies and how gaining her diploma might impact their future. She said, “Well, I'm studying, I mean, I have something in mind, hopefully things will work out, but I’m always going to be with Maurice”. Catalina shared a similar sentiment about Diego, “I'm going to take care of Diego as long as God gives me the strength to be able to carry him. I will always have him here with me.” These mothers recognise that their child will need intensive, daily care for their whole lives and that due to the difficulty in securing access to personal assistants, this will likely continue to be provided by them. Rather than striving for independence, mothers focus their efforts on reducing discomfort and improving quality of life for their child. One such example is how mothers understand the role of a wheelchair. There is a consensus among parents, clinicians, and therapists that children with CZS need a well-fitting specialist wheelchair with side supports and a footrest, to support their posture and protect their joints. Many children with CZS experience hypertonia (excessive muscle tone) or hypotonia (reduced muscle tone) that can impact posture (Massetti *et al.*, 2020), and many also develop hip dysplasia (Pone *et al.*, 2022). A well-fitted wheelchair can support good posture and prevent damage to the joints. Not having access to a specialist wheelchair puts children with CZS at increased risk of joint and muscle strain due to being unsupported and developing poor posture. Rita told me that Lola was developing scoliosis due to her posture. Once when I visited them at home, I noticed that Lola was sitting in collapsible pushchair that I hadn’t seen before. I asked Rita about it, and she told me that a friend had donated it to them when she moved away.

Rita: But look, these chairs don’t work for these children at all. Look how Lola keeps slumping to the side.

Ros: Yes, I see that. They need more support at the sides, right?

Rita: Yes, she does, because she's also starting to have a spinal problem. We need a *coche neurológico* (specialised wheelchair), that will help with her posture – the doctors have ordered it, but the EPS won't cover it.

Rita was engaged in a process of chasing up the EPS to request the order be granted so that Lola could get a wheelchair that gave her adequate support. Her primary focus was on the postural benefit rather than the independence that is often associated with mobility devices. Wheelchairs are first and foremost treated as a postural support to reduce pain and muscle strain, and secondarily as a mobility aid. Independence is not centred, and even with a chair, the children still need to be accompanied everywhere.

Breaking down binaries

Existing ethnographic research on families raising children with CZS has found that parents come to occupy the social position of a disabled person as they experience barriers and discrimination alongside their child (Greiner, 2022). The shared experience of barriers comes about through the relationship of care – mothers' role as the primary caregiver and role in leveraging access, discussed in the previous chapters, brings her into contact with barriers along with her child. This unsettles the relationship between impairment, environment, and disability established in the social model, and calls for a critical approach.

While societal attitudes towards disability have progressed, discrimination and lack of understanding persist. Andrea identified negative attitudes towards disability among the general public as a source of discrimination. She told me that when she takes Maurice out of the house, people treat them with pity; "you take him to the park and still people still give you funny looks and ask, "why is he like that?" They ask it with sadness." During a group discussion, Daniela told us about a time she took her two sons to the cinema, and that another customer had made a disapproving remark to her about bringing Eduard with her, due to his disability. As primary caregivers, Andrea, Daniela, and the other mother-carers are the main recipients of insensitive remarks about their children's conditions. As I have already discussed, discriminatory attitudes towards mothers of disabled children in

particular are underpinned by not only ableism but gender discrimination. Social responsibility for the welfare of children is ascribed to mothers, and the interaction of this gendered stereotype with an understanding of disability as a deficit results in discriminatory treatment of mothers of disabled children.

Several mothers explained how they tried to educate people who made ableist remarks, correcting their language and explaining why the comment was offensive or inappropriate. I saw this in action one day when I accompanied Patricia to the Secretary for Education to inquire about registering Dalia at a new school. Patricia left Dalia at home with the nurse rather than bring her along; this meant she could use the bus to make the long journey to the office, and that Dalia's routine would not be interrupted by a day sitting in a waiting area. When we got to the building that housed the Secretary for Education, a security guard directed us to a reception. I hung back while Patricia spoke to the receptionist. She sent us through to a separate waiting area, and once we were sat down out of earshot of the reception desk, Patricia asked me if I had heard her interaction with the receptionist. I said I hadn't, and she relayed it; "she asked me "does your daughter have a problem?" and I said "no, she has a disability". Sometimes people say things like that, they say something negative when they mean disability, so I tell them no". Patricia identified that the receptionist's language conflated disability with a flaw or 'problem' and corrected her. Here it is the affective dimension of care that prompts Patricia to intervene on Dalia's behalf and correct the receptionist's language.

Hilaria told me that she and Máximo stayed at home during the entire peak of the COVID-19 pandemic. She said was not particularly worried about the risk of the virus to herself or her husband, but they worried about Máximo, so she stayed home with him. The world was not set up to keep Máximo safe, and Hilaria experiences those consequences alongside him. The relationship of care between Hilaria and Máximo is central to her shared experience of social isolation. Here care as both a feeling and a set of behaviours is clear; Hilaria identified that Máximo was at increased risk of complications if he were to be infected with COVID-19 and chose a course of action to minimise that risk.

Andrea told me that when families are denied services or have to wait a long time for access, "we suffer". Later in the interview she clarified, "So that I can be clear, those who suffer are the children and the mothers". Barriers to services, denials of access and discriminatory policies cause suffering not only to the person with the disability but to the carer who navigates exclusionary systems on their behalf. It is the mothers in particular who suffer alongside their children due to their position as the primary caregiver and role in navigating services and negotiating access. Patricia put it succinctly when she recounted a comment that another mother-carer had made that resonated with her, "we are patients too. We spend a lot of time waiting, and it tests the patience". Through the embodied experience of barriers and exclusion, mothers experience some of the disadvantages faced by their disabled children. The effects of disability discrimination extend beyond the individual with the impairment. This is an example of 'disability discrimination by association', which is gaining more recognition, in part due to a recent decision by the UN CRPD (2022) recognising the existence of such a phenomenon.

Conceptualising a rigid separation between the "self and other… body and society" reflects a Eurocentric perspective on the nature of being and the self (Goodley and Swartz, 2016). Indeed, there is a wealth of anthropological literature which suggests that people in the global south "conceptualise themselves as more continuous with those around them" than the dominant, Eurocentric perspective suggests (Grech, 2016, p. 72). Rodríguez (2020) suggests that through close, affective relationships of care, "various leaks occur between bodies, [and] co-extensions of one body into another are generated" (p. 209) which trouble Eurocentric notions of independence and the unidirectional nature of relationships of care. Relationships of care are at the centre of how mother-carers experience disability discrimination by association. To return to Goodley and Swartz (2016), mother-carers experiences of caring for children with CZS are at once embodied, socially constructed and affective. It is through their embodied experiences in the world with their child, the societal barriers they face together and the affection and care between them, that mothers come to occupy the social position of a person with a disability.

Interembodied debility

The idea of impairment as a distinct concept from disability is key to the social model of disability. Impairment has become naturalised within the social model, but critical scholars argue that impairment too is socially mediated (Hall, 2019). Puar (2017b) articulates the concept of debility in order to capture the social production and stratification of impairment under neoliberalism. The exhaustion of people and populations is stratified according to existing socio-political hierarchies, and disabled people and their carers are among those at the sharp end of these systematic processes of 'wearing out' (Goodley, Lawthom and Runswick-Cole, 2014; Puar, 2017b). Williamson, Engel and Fietz (2023) add an explicitly feminist dimension, highlighting the debilitating nature of gendered care for disabled people under neoliberalism in times of crisis (in this case, the COVID-19 pandemic). In this section, I bring together the concepts of debility and interembodiment to demonstrate how state neglect of disabled children can produce and worsen impairment for both them and their caregivers.

Bunkley (2022) developed the concept of interembodiment to "illustrate the shared sense of illness that transgresses discrete biological bodies" based on her research with people with non-communicable diseases and their family caregivers in Senegal (p. 256). Her conceptualisation of interembodiment troubles the notion of separation between bodies as well as the distinction between communicable and non-communicable diseases. I have already discussed how mothers come to occupy the social location of a disabled person through their experiences of exclusion and discrimination by association, and shown that this is mediated through the close relationship of affective and practical care. Bunkley (2022) finds this to be the case also for interembodiment, as the embodied experience of the illness of one are "transmitted" to the other through the "deep connections" between the two parties (p. 269). Here, I use the concept of interembodiment to explore how mother-carers are debilitated by the ableist neglect and discrimination directed at their children.

Mother-carers recognise that they are expected by the state to sacrifice their health and wellbeing if necessary to care for their child. During the third group discussion, the conversation turned to my imminent return to the UK to begin analysing data and writing up my thesis. They asked what I would write in my thesis, and I explained the main topics I wanted to write about – about their lives with their children, struggles with the EPS, access to suitable services, and the barriers posed by inaccessible transport. Veronica pointed out the importance of highlighting the expectation that "one must be dedicated 100% to the child, so how is the mother supposed to eat?" Catalina re-iterated the question, "how does the mother eat?". With their questions, Veronica and Catalina highlight that mother-carers are expected to sacrifice their wellbeing in order to dedicate themselves to care work. Beatriz added that, "there is supposedly meant to be help for mother-carers, but when will we get it?" The lack of support and limited political will to correct it is glaring to mothers, who can clearly identify an unmet need for support. Mother-carers recognise that they are expected to take up the slack, but they do not accept the status quo, and rather continue to call for greater support for carers.

Mothers highlighted that their child's good health is contingent upon them remaining well. Andrea explained how Maurice's wellbeing depended on her own: "If the carer is well, the patient will be well. Because look, when I am in good health, when I'm not in pain, when I'm energetic, when I have a positive attitude, I'm going to do a good job of looking after Maurice, I'm going to care for him well. But a sad, overwhelmed person, as I have been in the past at certain moments, they would scold him. I have scolded him, and he understands, and he cries in anger, and he can understand that I am scolding him. So that's something they understand, even with their condition, with their disability, they understand". While mother-carers act as a shock absorber, sacrificing their own wellbeing to care for their child, they are unable to fully absorb the effects of discrimination and neglect. Rather than directly impacting the child, these effects reach them through the mother-carer, whose ability to care for them is diminished by the debilitating routine of care. Mother-carers and their children both experience state neglect and discrimination, and the impact on one is transferred to the other through the relationship of care.

Seizures, insomnia and exhaustion

Mother-carers are constantly vigilant about the child's health, especially concerning seizures. They worry about the child having seizures in the night, and as a result they sleep lightly and wake often, looking out for signs of a seizure. Andrea explained how this constant vigilance impacted her sleep like so: "I don't sleep well anymore, not since Maurice was born, I haven't gone back – and I know I'm never going to go back – to sleeping for eight hours, which is how long one should sleep. Because any noise wakes me up, a snuffle or a snore from him, because I have to be aware. Is he breathing, is he okay?" At a group discussion, Rita told the other mother-carers about a conversation she had with a paediatrician about allowing Lola to sleep independently. "The doctor told me that I should let her sleep on her own. I do understand why she says that, but I'm scared because she has convulsions at night, so I don't want to leave her alone to sleep". Julia joined in and said, "it's the same for us; because of the convulsions I'm scared to leave him alone". Hilaria concurred, explaining that, "when he started having the convulsions, I started to sleep with him at night; I was really scared I just wanted to be able to get to him quickly if he started to a seizure". Andrea agreed, she said, "that's why we have him in the room with us, we can't sleep apart from him. Sometimes his breathing might stop, and he also has convulsions. When he has them, it seems as if he's awake but actually, he's not really there". Before they were granted round the clock nursing care, Patricia told me that if her sister was at the house, she slept in the same bed as Dalia in order to keep an eye on her. "If not, I worry a lot, and I check on her all night, and the I am very tired". In a study of caregivers for children with CZS in Brazil, history of seizures in the child was found to be associated with caregiver anxiety (Gama *et al.*, 2021). This resonates with my observations that seizures are one of the symptoms that mothers find the most concerning, and that require constant vigilance. As already discussed, several children in this research had gone for periods without access to anti-convulsant medication due to stock outs or insurers refusing the authorise their prescriptions. Mother-carers fear that a seizure could be debilitating to their child, setting back gains in cognitive and motor function made through regular therapeutic intervention. Lack of access to

support from paid carers and gaps in access to medication means mothers are forced to sacrifice their own wellbeing by prioritising keeping an eye on their child over getting a full night's sleep. Over the course of months and years, the lack of sleep lead to a constant state of physical and emotional exhaustion for the mothers. Mothers forgo rest in order to protect their child's nervous system from damaging seizures, and in the process become exhausted and less able to provide effective everyday care.

Wheelchairs, posture, lifting and stress

As discussed earlier, a specialist wheelchair fulfils several functions for a child with CZS and their family. A well-adjusted wheelchair functions primarily to support the child's posture and reduce strain on their muscles. Having a suitable wheelchair also facilitates participation in family life, as children can sit in their chair and be safe and supported in common areas of the home. Without a wheelchair, children spend a lot of their time lying on their beds. Even though navigating narrow, uneven pavements with a wheelchair is challenging, having a chair nonetheless facilitates participation in events outside the home as well. For mothers, having a wheelchair reduces the risk of injuries like muscle strains from lifting and carrying the child.

Mothers recognise the importance of a wheelchair as a therapeutic tool, a safe seat for the child, and a mobility aid. Having a wheelchair also reduces the risk of injury from carrying for the mother. As a result, not having a wheelchair was concerning to them, and chasing up providers and insurers to try and get access to a wheelchair for their child was a source of frustration. Dalia had a wheelchair, but she had grown out of it and needed a new one. Patricia explained the process she had been engaged in to try and get Dalia a new specialist wheelchair. "I called the person in charge as they still hadn't given me the chair. It has been paid for [by their health insurance provider], but they haven't given me the chair. So now Dalia is going to be enrolled in school and still we won't have the chair. Without the chair she can't attend school. These are the little things that make me… how to put it? Psychologically tired. I don't know, it's mentally tiring and yet I haven't achieved anything. I feel like I have done nothing. I mean, I'm trying, but since nothing comes out of it, I feel like I haven't done anything. It's a mental exhaustion that you get

because you call, and they don't answer. Then when they do answer me, they say, "no, just wait", so that's very stressful as well."

At the Secretary for Education the assessor explained what they would need to do to facilitate Dalia's attendance at school in person, including the requirement that she would need her own wheelchair in order to attend. With the clock ticking to ensure Dalia had the right equipment to be able to start the new school year with her classmates, Patricia was feeling demoralised at the slow process and lack of response from the service provider who was supposed to be supplying the chair. Not long before our conversation about the wheelchair, I had accompanied Patricia and Dalia to a therapy session where the occupational therapist emphasised the importance of regularly correcting Dalia's posture to reduce the strain on her back and over-extension of her joints. She explained that if Patricia could help her maintain good posture at home, they would be able to make more progress in therapy. Patricia listened and added that a well-fitting specialised wheelchair would help as it would keep her torso lifted and support her feet to keep her legs straight, but that they didn't have one. The delay was debilitating to both of them – Dalia's joints were under strain and her progress in occupational therapy was hampered as it was difficult for her to maintain good posture consistently at home. Patricia was emotionally exhausted, stressed and discouraged, and had also developed a strain injury to her shoulder from lifting and carrying Dalia. The long wait for a suitable replacement wheelchair was debilitating to both Dalia and her mother. Over time they were coming to embody the neglect they faced from the state in different ways.

Care, discrimination, and debility

I find the concept of debility particularly appropriate here as it directs attention outwards to the structural factors that debilitate both children and their carers, rather than framing the child as a burden or drain on the mother. Academic literature on complex childhood impairment often implicitly adopts this lens (Ryan and Runswick-Cole, 2008). In their article on 'burden in caregivers of children with congenital Zika syndrome', Filho, Sena and Wajnsztejn directly point to the

complexity of the child's impairment as the cause of "mental and physical burden to caregivers", without mention of societal oppression and discrimination (2023, p. 2). By way of contrast, Jaramillo, Moreno and Rodríguez (2016) identify the parenting role as burdensome rather than the disabled child, and highlight external support as an important protective factor against emotional exhaustion. They found that emotional exhaustion was more prevalent among mothers of disabled children than among fathers (Jaramillo, Moreno and Rodríguez, 2016). This points to the social role, concentration of responsibility, and lack of support as the source of burden and overwhelm, rather than the child's characteristics.

Debility also offers a frame for a critique self-sufficiency, a neo-liberal value uncomfortably close to the independence championed within the social model. Self-sufficiency is a liberal idea underpinned by ableist norms about the body and ways of being (Hernández, 2020). Self-sufficiency is valorised as the binary opposite to fragility, which is de-valued and rejected (Hernández, 2020). By placing full responsibility for the wellbeing of children and the population with female caregivers, self-sufficiency acts as a foil for state neglect and discrimination. The analytic lens of debility reveals that, far from being the opposite to fragility, systems that prioritise 'self-sufficiency' over providing for populations in need of support actively contribute to fragility by wearing down the emotional and physical health of populations.

Bringing debility together with interembodiment illuminates how children and carers wellbeing is interconnected. Neglect of the child by the state through negation of their rights is transmitted to their caregiver through the close relationship of care, debilitating both the child and their caregiver. This framing contextualises slow disablement of mother-carers in relation to ableism, patriarchy and familism.

Concluding remarks

Mother-carers interpretations of their child's disability cannot adequately be defined by a single static model. They highlight the existence of social barriers that exclude their child and push back on pathologising narratives that construct

disability as an inherent flaw. Their interpretations go beyond the social model as it is articulated in mainstream disability studies, and I have shown that a more critical approach can help to illuminate the interconnected embodied, social, and affective dimensions of care work, disability, and debility. Mother-carers understand disability as an embodied way of being in the word that is part of human diversity. Rather than viewing their child's impairment itself as a harm, they identify pain and discomfort as harms that they struggle to accept and strive to alleviate. They prioritise comfort over independence, and highlight the interdependence of their and their child's wellbeing. Close relationships of care blur the lines between individuals, bringing them into such proximity that embodied experiences of neglect, discrimination and debility are shared (Rodríguez, 2020). Patriarchy, familism and ableism interact to produce disability discrimination by association directed at mothers. This has been observed in the literature on CZS, but has not been explicitly named as such to this point.

Familist disability policy positions the mother-carer as the only line of defence for the child's health and wellbeing under conditions of state neglect. As such, mother-carers mental and physical health is worn down by the struggle to promote their child's rights to health, education, and full participation without adequate state support. As these accounts demonstrate, disability discrimination in conjunction with neoliberal, familist welfare policy begets further debility and impairment. Through the relationship of care, discrimination directed at the child has an effect on the mother-carer. Lack of access to appropriate resources and technologies to support the disabled child leads to worsening impairment in child and the production of new mental and physical impairment in the parent. Structural ableism, familism and patriarchy burdens both mother-carers and their children, producing interconnected debility. Their social positions and embodied experiences are highly porous and interdependent. In the following chapter I will show that this interdependence is temporal as well as embodied.

Chapter 7: Towards collective futures

Introduction

This chapter is about how mother-carers experience time and how they are working to shape the future for themselves and their children. The arguments developed here came about through an iterative process of engaging with theory development and application, primary data collection and reflexive analysis. Based on my knowledge of the literature on disability and temporality, I wondered how the participants in this research would speak about time and the future. During informal interviews, participants spoke at length about the past with little probing, and the minutia of everyday life made up the bulk of informal discussions. However, they seldom spoke about the future beyond the next appointment. Initial analysis of data revealed an absence of discussions of the future. Based on this, I included questions about the future in interview topic guides, and I analyse the participants' responses here. In further rounds of analysis, I found that one aspect of the future was discussed organically. Mother-carers often discussed, both individually in participant observation and together in group discussions, their plans to reestablish the *fundación* that they had been working together on before the COVID-19 pandemic. Iterative, reflexive data collection and analysis enabled me to identify these themes through their absence and flexible methods of long-term engagement with participants gave me the opportunity to follow up with direct questions. Based on these observations, in this chapter I analyse the relationship between temporality and activism for mother-carers. I will first explore mother-carers' relationships to time and the future in the context of their child's disability, taking Williamson's work on "the temporality of Zika" (2018, p. 685) as my point of departure. I will discuss mother-carers experiences of the present and the passing of time, drawing together Robertson's concept of "disabled maternal lived time" (2015, p. 2) with Vallega's (2014) notion of ana-chronic temporality to expand upon Williamson's (2018) finding that mother-carers experience "crip time" (Kafer, 2013c) with their child.

Next, I turn my attention to the future. Mother-carers' considerations of their individual future with their child were characterised by uncertainty, frustration and the threat of debility, reflecting their supposition that they would continue to lack adequate support to care for their child. However, they also envision a future of mutual aid and self-organisation, which is more hopeful. Understanding disabled maternal lived time in this context lays the foundation for a discussion of maternal micro-activism and grassroots organising, viewed through a lens of "micro-activist affordances". Mother-carers wish to sustain the affordances they create through the formation of a grassroots organisation. While for each family, the present is shaped by ableism and neglect, they envision a shared future that is made more accessible through peer support and collective action.

Theorising disabled lived time

Kafer (2013c) brings critical disability studies into dialogue with queer temporalities to develop her theorisation of crip time, which refers to the unique relationship between disability and time. This theory has also been applied to caregivers' experiences of raising young children with disabilities in a number of different contexts. Williamson (2018) finds that "in their close, often near-constant contact with the child, mothers also experience crip time" (p. 5). In order to explore the maternal experience of crip time, I bring together Robertson's concept of "disabled maternal lived time" (2015, p. 2) with Vallega's notion of ana-chronic temporality (Vallega, 2014). Both Vallega and Robertson theorise *lived* time – temporality as it is shaped by embodied experiences and subjectivities. Vallega (2014) puts forward a decolonial critique of Western linear time and its entanglement with linear development narratives. He builds upon the work of Quijano to argue that Latin American history is neither singular nor linear, but rather composed of a dense network of overlapping temporalities (Vallega, 2014). Within this framework, Latin American temporality is characterised by simultaneity and multiplicity rather than singularity and linear progress.

"Disabled maternal lived time", or the temporalities lived by mother-carers of disabled children, is also non-linear (Robertson, 2015). A mother to a disabled child herself, Robertson (2015) finds that mother-carers experience temporal dissonance characterised by "interruptions" to everyday "repetitions". Mothers engage in repeating cycles of everyday gendered care work (Robertson, 2015). Rather than being uniform however, these cycles are subject to continual interruptions due to the unpredictability of raising a young child. For mother-carers of disabled children, interrupted yet repetitive acts of caregiving and social reproduction are often extended in duration based on their child's need for additional support (Robertson, 2015). The unknowable future also dominates and interrupts the cyclical present (Robertson, 2015). In this way, disabled maternal lived time is "ana-chronic", as the present and future bleed in to one another (Vallega, 2014, p. 115).

Disrupting normative timelines

Fisher and Goodley (2007) point to the Western, modern notion that the human life course should follow a linear trajectory of continual progress and development as an underlying principle of the biomedical model of disability and the preoccupation with rehabilitation. Among mothers of children with disabilities in England, they found that such narratives "can obstruct the development of positive discourses around disability" as the expected life trajectory may not be possible for people with certain impairments, and thus their lives are constructed as deficient, lacking in potential and inherently tragic (Fisher and Goodley, 2007, p. 78). Countering these narratives, as some of the mothers they encountered were able to do, enabled parents to engage with the child on their own terms and see their child's strengths and positive attributes more clearly (Fisher and Goodley, 2007). In her ethnography of mothers of children with CZS in Bahia, Brazil, Williamson (2018) identified similar counter-narratives based on rejecting linearity and developmental 'progress'. She draws on the notion of crip time to interpret the construction of these counter-narratives (Williamson, 2018). She found that parents responded to uncertainty not by abandoning hope for the future but by practicing hope in the present (Williamson, 2018). Mothers responded to the unpredictability of their child's condition by developing "alternative forms of thinking about, interacting with, and

appreciating the child in her or his own terms" rather than feeling beholden to developmental milestones that may never be met (Williamson, 2018, p. 2). In doing so, they rejected normative time and constructed "temporal trajectories that conform to the child, and not the other way around"(Williamson, 2018, p. 12).

In line with Fisher and Goodley (2007) and Williamson (2018), I identified that mother-carers had developed alternate ways of thinking about time and the future with their child. One way that mothers expressed this was through the idea of living in the present. Julia told me that she and Stefano take things day by day. She said, "I just have to make sure he gets his therapy, to be with him and share those moments – to go to the park, a birthday, Christmas, a celebration… Just relate to him and make sure he lives each moment the best he can, and so that I can remember all those moments with him". Julia acknowledges the passage of time when she talks about making memories, but her relationship to Stefano is nonetheless orientated towards the present.

The idea of going at the child's pace was also invoked by mothers to express their acceptance of an alternative way of being and experiencing time. Children with complex impairments disrupt normative time(lines) and parents come to accept this over time (Fisher and Goodley, 2007; Williamson, 2018). Rita told me about a debate she had with the audio-phonologist who was working with Lola to develop her ability to chew and swallow. She told me that the therapist had pushed her to swap Lola's flexible silicone spoon for metal cutlery, but Rita disagreed with this course of action. She said, "she is really sensitive to the metal spoon, so if you use that she's not ging to open her mouth and she won't eat. [The therapist said] "no, that's why you have to teach her…" But these things are step by step. You can't just… She's accustomed to the silicone spoon. If you go in right away with the metal one, no, she's not going to eat. So, it has to be one step at a time, yes, one step at a time. On that part we did not agree." Rita has adjusted her expectations of the pace of change in their lives according to Lola's symptoms and capacity. This is evident in contrast to her perception that the therapist was trying to impose an unrealistic expectation on them to show 'advancement' or progress towards a goal. Children with CZS and other complex impairments represent a rupture to normative time. In

order to reconcile this rupture, institutions adopt a 'curative' outlook on the future (Kafer, 2013c). Within this perspective rests an implicit assumption that disability will be intervened upon in order to normalise the disabled subject. Kafer (2013c) finds that "within this frame of curative time, then, the only appropriate disabled mind/body is one cured or moving toward cure" (p. 28). Rita is concerned with feeding Lola, maintaining her weight and ensuring she is well nourished. This can be accomplished using the silicone spoon which Lola accepts. For Rita, there is little benefit, and substantial potential cost, to transitioning to using a metal spoon. The therapist's interest in changing Lola's cutlery appears to be motivated by an (unconscious) desire to 'normalise' Lola's feeding, bringing her closer in line with other children of a similar age, rather than being driven by a concern for her present day health and wellbeing.

'Every day is the same'

Robertson's (2015) conceptualisation of disabled maternal lived time centres on interruptions and repetitions. Mothers in this research expressed the repetitive nature of their lived temporality when they told me that 'every day is the same'. The first time I visited Patricia at home, she told me to come early so I could spend the day with her and Dalia. When I arrived at 9 am she showed me around the apartment and introduced me to Dalia, who had just woken up. We chatted for a while, and then Patricia started her daily routine in earnest. She gave Dalia a bath, dried her off, combed and plaited her long, curly hair, moisturised her skin, put her nappy on and dressed her. By the time Dalia was washed and dressed, it was late morning and we moved through to the front room of the apartment so that Patricia could start preparing lunch. She cooked the meal, cut up Dalia's portion and fed her, ate her own meal, and washed up the pans and plates. As she was sweeping fallen grains of rice up off the floor, she remarked, "now you see Ros, every day is like this". Patricia's statement reflects the repetition of the mundane, the cyclical nature of bathing, dressing and feeding that characterises her role as a mother, and the extended nature of Dalia's dependence on her compared to a child without an impairment.

While Patricia's statement reflected a fairly neutral view towards the repetition of the everyday, Andrea brought my attention to how ableist discrimination confined her to a repetitive temporality as she tried to make things better for Maurice. She said, "Sometimes one becomes tired, it's a constant fight. It's a cultural issue, things are not accessible. Every day is the same, and it affects you emotionally. Sometimes I don't want to do it anymore, going to appointments, fighting with the EPS." Andrea's frustration at being engaged in a constant cycle of fighting for Maurice's rights demonstrates how ableist structures produce repetitions and interruptions to disabled time, even as they presume a shared normative, linear temporality.

'I don't [like to] think about the future'

I collected and analysed data iteratively, coding fieldnotes and transcripts in order to identify new lines of inquiry and areas to follow up on. Through this process I identified that the future was rarely discussed. This was particularly noticeable in contrast to discussions of the past. In initial meetings with participants, I usually asked a question along the lines of "tell me about your child" and many participants spontaneously talked me through their child's life chronologically from the time they found out they were pregnant. After noting this absence, I decided to raise the topic of the future by asking about it directly. The initial response I received reflected the sentiment "I don't think about the future", and upon some further discussion, was often clarified as "I don't like to think about the future".

Not thinking about the future is related to the uncertain prognosis for children with CZS, together with the precarity that mother-carers face in their everyday lives (Williamson, 2018). When I asked Andrea about her future with Maurice, she paused for a long time, and then said, "That is tough, you're the first person who has asked me that question. It's not easy, I haven't thought about it… With Maurice and I, we take it day by day." Continuing the discussion of her future with Maurice, Andrea said, "It's hard to say, because there are cases of children, well – people, with cerebral palsy who live many years. I'm talking about someone aged 30 years.

I've seen adults with cerebral palsy since birth, you see? But, the future, Maurice… Well, let's put it like this. I... Well, it sounds bad, but it's the reality. As a woman, as a mother, I am preparing myself for the day I will be without Maurice." The uncertain prognosis for children with CZS looms large in Andrea's imagination when she thinks of her future with her son.

Other mothers explained that they tended to think in terms of managing one thing at a time, or sorting out the most pressing issue before moving on to the next. For these mothers, taking things day by day is not only related to the uncertain prognosis, but also a feeling of overwhelm at the number of tasks the mother has to do. I visited Rita shortly after she had visited the Secretary for Education to identify a suitable school for Lola to attend in the coming academic year. She told me about the meeting, and I asked her, "so, by January, Lola might be attending school?". Rita replied, "I don't know, we will have to see. First of all, we need to make appointments with all the specialists. They will evaluate her, check her over, do everything, see how she is doing… But on a personal level, it's also difficult for me to send her, to let her go... It's scary, I don't know." Rita had changed to a new EPS to try and get better services for Lola, and since making the change she had been trying to schedule specialist appointments for Lola. These had been ordered by their paediatrician in August, but by the time of our interview in November, she still had not been given any appointments. Due to this delay, the school year was soon to start and the tasks that Rita had to complete were piling up. Looking towards the future was overwhelming, so Rita tried to stay focused on the most pressing tasks in the present moment. The upcoming school year represented a point in time with a fixed start date that could easily pass them by, leaving Lola waiting another year to enrol in school. Rita was trying to look towards the future and make arrangements to meet this deadline, but the delays from the EPS in granting Lola specialist appointments interrupted this planning and brought Rita "back into the realm of the immediate" (Baraitser, 2009, p. 68, in Robertson, 2015). While taking things day by day is sometimes reflective of going at the child's pace and not rushing, it can also represent getting stuck in the present waiting for unreliable or unresponsive service providers.

The present and future simultaneously dominate Rita's lived reality - planning for the future is interrupted by the present, while the present is steeped in uncertainty about the future. While in Robertson's (2015) conceptualisation of disabled maternal lived time, the present and future are entangled yet distinct, Vallega's (2014) contributions on simultaneity in ana-chronic time helps us to see the competing dominance of present and future in the case of mother-carers temporalities in Colombia in the context of CZS.

Interruptions and repetitions

Robertson stresses that our consideration of interruptions to maternal temporality must be contextualised with repetitions (2015). Not only do mothers have a lot of responsibilities to address, but their ability to do all of the tasks on their to-do lists is hampered by interruptions. Hilaria returned to Venezuela with her husband and children to spend Christmas with family. While they were there, Hilaria fell while carrying Máximo and he broke his femur. He was rushed to hospital for emergency surgery, and had a further procedure in January. I visited them in early February once they had returned to Barranquilla and Máximo was recovering at home with his leg in a plaster cast. With the emergency behind them, the holidays over and the new year underway, Hilaria talked me through her to-do list for the coming months. She said, "we have an appointment with the paediatrician tomorrow, I need to ask for a new order for nappies as we have run out. They have to be re-ordered every 3 months. Máximo has a little rash that I want the paediatrician to look at too. And I'm also going to request a nurse soon. But first, we'll focus on getting the stitches taken out, recuperating more, and then we'll think about nurses. After that, it will be a wheelchair and transport." Máximo will probably need to use nappies for his entire life. The constant cycle of requesting nappies, receiving the order, and fulfilling it at the pharmacy every three months creates an artificially urgent and yet predictable repeating task. Máximo cannot go without nappies, and Hilaria cannot get access to them without requesting them from the doctor, so longer term goals are pushed further down her list by this ever-present task of the present moment. Hilaria's efforts to secure better care for Máximo in the future are hampered by the repeating interruption of re-ordering nappies for her son.

The requirement to make repetitive requests for resources like nappies is reflective of a normative linear model of childhood development in which the child's support needs are expected to decrease over time, facilitating a transition to independence (Kafer, 2013c). The disconnect between this model of development and the trajectory of childhood disability results in mother-carers being subjected to repetitive interruptions, inhibiting their ability to make and execute longer term plans related to their child's care.

Williamson (2018) finds that the unpredictability of CZS combined with the everyday precarity that young, poor, racialised mother-carers face precludes them from thinking about the future. Further to this, I have shown that ableist, neo-liberal state systems create interruptions and perpetuate the repetitive, gendered care labour of the present. Uncertainty about the future looms large, but future planning suffers interruptions that bring mother-carers back into the present to deal with pressing issues relating to their child's care. It is true that the children have increased care needs that intensify the repeating cycle of reproductive labour. Their impairments can be unpredictable and everyday life for mother-carers is punctuated by interruptions due to illness, seizures, or other symptoms. However, the very systems that are supposed to support and enable disabled children and their caregivers in fact contribute to the cycle of repeated interruption. Children with CZS deviate from the normative linear process of 'typical' child development (Kafer, 2013c), and health and care systems and services are unsuited to their unique temporal existence. The temporal mismatch produces interruptions that further intensify the mothers' repetitive caregiving routine. The health insurance company is orientated towards a "curative future" (Robertson, 2015, p. 9), which pre-supposes a time when Máximo will no longer need to use nappies, and thus burdens Hilaria with a repetitive routine of requests and authorisations for a resource she knows they will likely need for Máximo's entire life. As Robertson puts it, "focusing on creating a better future for our children leads to 'an ethics of endless deferral', as we work towards a future cure rather than assisting disabled people to live more fully in the present" (2015, p. 9) This is evident in Hilaria's experience with Máximo. Tasks that would provide Máximo with greater access or daily comfort are deferred in service of repetitive tasks that imagine a day when the child's impairments will be 'cured'.

Mother-carers temporalities are impaired by neo-liberal ableist systems that keep them in a perpetual present and preclude meaningful investment in future planning.

Debilitating futures

When mother-carers do think about the future, they think about the child getting bigger and heavier, while they themselves become older and more frail. Mothers worry that as time goes on, caring for their child will become more difficult. One day at Hilaria's we were all sitting on the bed, Máximo was lying on some cushions wearing pyjamas. Hilaria tugged on the trouser hems, which were a few inches above his ankles. She said "oh no you've grown out of your trousers! Next thing you know, you'll be bigger than me – what will happen then?" Hilaria's joke reflected sincere conversations I had with several other mothers. I asked Catalina what she thought might change about their life as Dominic grew up. She said, "it'll be difficult, because he's already getting big, and one day I won't be able to carry him. How will I bathe him? So, it's difficult. He's a big boy. In fact, I was just bathing him, and I said, "young man, you'll have hairs on your chest in no time!" That was just this morning". Andrea shared a similar reflection. She told me, "We've had the nurse for nearly two years now. By the time Maurice was three, I knew I needed more help. Imagine when he gets even bigger – yes, I need help". These concerns are doubtless connected to the debilitating conditions of caring, and pre-suppose a future in which they and their children are still denied access to appropriate supports such as nurses, wheelchairs, and accessible transportation.

Julia brought together the uncertain prognosis with concerns about her declining strength when she said, "For as long as God gives him his health and gives me my strength, I'll take care of him." Not knowing how long she might have with her son shaped Julia's view of the future and relationship to time. Rather than trying to plan ahead, or making assumptions about what the future might bring, she is committed to care for him for as long as she can. While she does not know how Stefano's condition will develop in the future, she does suggest that the trajectory of her own health is more predictable – as she ages, she anticipates that her ability to are for

him will decline. The interdependence between the health of the mother and child is clear in her statement, as when Julia says "as long as God gives him his health and gives me my strength" she raises the issue of mutual debility once more.

Fleeting affordances

As I discussed in the previous chapter, through close relationships of care and experiences of discrimination, mothers come to occupy the social position of a person with a disability. Taking this together with the finding that mother-carers experience a unique temporality based on their embodied subjective positions lays the foundation for a discussion of maternal micro-activism. Importantly, mother-carers engage in micro-activism simultaneously on their own behalf and that of their child – they are working to create affordances in a world that discriminates against them together with their child.

Mothers' statements about taking things day by day or living in the present must not be read as passivity towards the future. Indeed, their child's condition is unpredictable, and the environment they are in can appear unyielding or rigid (Dokumaci, 2019). Nonetheless, within their ana-chronic, looping temporality, mother-carers produce fleeting 'micro-activist affordances' (Dokumaci, 2016). In doing so, they alter the potential accessibility of their environment for themselves and their child through interacting with it.

Dokumaci conceptualises 'affordances' as the potential or possibility in an interaction between "an organism and its environment" (Dokumaci, 2016, p. 79). The potential arising from such an interaction is dependent upon the characteristics of the environment (or an object within the environment) and the particularities of the individual interacting with it (Dokumaci, 2016). Disabled bodies disrupt the norms of an ableist society, and thus, affordances taken for granted by able-bodied subjects may be unimaginable or inaccessible to a disabled person (Dokumaci, 2016). As a result, disabled people engage with their surroundings in non-normative ways. The potentiality of an object or structure is thus transformed when a disabled subject interacts with it, and thus micro-activist affordances create a possibility within an environment shaped by ableist norms that was previously absent

(Dokumaci, 2016). The affordances created by disabled people in their interactions with the environment shape the world, sometimes in almost invisible ways (Dokumaci, 2016). Dokumaci names these interactions 'micro-activist affordances' in recognition of their political character. Dokumaci (2020) further theorises 'people as affordances' within the category of 'micro-activist affordances'. This means that another person acts as an intermediary between the disabled individual and their environment, again transforming the potentiality of the interaction (Dokumaci, 2020). Dokumaci's theorisation offers us new ways of understanding care, and also provides a lens to view how "one person dwells in another's experience of disability" (2020, p. S104). As I have also found in the previous chapter, through shared navigation of ableist spaces and close relationships of care, disability becomes a shared experience (Dokumaci, 2020). For mother-carers of children with CZS, ableism impacts them together with their child, as discussed in the previous chapter, and affordances are similarly entwined. I extend Dokumaci's analysis by examining mother-carers interactions with resources in their environment that comes about through their performance of gendered care work. Mother carers seek out and interact with these resources with the aim of creating possibilities, however fleeting, for their child to exercise their rights to health, education, and participation. Taking a feminist perspective to Dokumaci's theory, I develop a theorisation of 'mother-carers as affordances' (Greiner and Avery, 2023; Avery and Greiner, forthcoming).

Mother-carers as affordances

Dokumaci (2019) finds that disabled people "bring into being what is otherwise an inherently absent world-counterpart" through their interactions with the environment (p. 513). I find the idea of creating a potentiality that was otherwise absent (due to ableism) particularly illuminating when analysing mother-carers interactions with one another. Mothers bemoaned the fact that there is no single source of information, no pamphlet or office that can tell you all you need to know as a parent of a disabled child. In a group discussion, Andrea was telling the group about a connection she had made with another mother-carer of a child with cerebral palsy who she met by chance in a waiting room. I asked if this was quite

typical of how people get in contact with each other and find out information. She said, “yes, it’s always very much word of mouth. You just kind of overhear someone talking or meet people in waiting rooms. There's no unified system of passing out information to parents. It's just by luck that you run into the right kind of person.”

As discussed in Chapter 5, mothers share information between them in order to help each other navigate health systems and gain access to services and resources. Patricia explained to me how information travels by word of mouth. “So, it travels like that, successively, from one to another. If she does well with this or that, she’ll tell the next person [how she did it]. So, like that, word travels”. I followed up and asked if there was any kind of resource or guide that parents could turn to for information. Patricia replied, “No, no. The only guide you have is the experiences she has already had, the experience she has lived, and what she has learned from others. Without that guide, you can’t achieve anything.” In this statement Patricia emphasised the essential nature of this word-of-mouth peer support. When she says that “without that guide, you can’t achieve anything”, Patricia shows that mother-carers information sharing within peer networks have created an otherwise absent potentiality. As a collective they have gathered information to guide other mother-carers, and thus brought something into being that was previously absent. They create affordances not only for their own child, but for others who face similar barriers.

Micro-activist affordances are distinguished from other acts of improvisation by the way they (fleetingly) expand the worlds of disabled people. Mother-carers exchange information on how they obtained medication, schooling, nurses, and transport for their child, creating new possibilities for others to gain access. Patricia elaborated on the kinds of information shared by mothers in informal networks, and how this influenced access to care. She said, “if you want to get nurses, first of all you have to get nappies. This is something that the EPS uses to show the dependence or independence of the child. If you haven't asked for nappies and got them, then they assume that the child is independent, and they don't need nursing care. So, this seems to be a criteria that the EPS are using. If the child can use the toilet, they are not dependent and don't need nursing care. People might not know this. It's not

obvious, but it's essential." Through experience, mothers have learned about the rigid criteria that health insurance companies use to determine need. Dependence and independence are constructed as a binary by the insurance agencies, rather than being understood as a dynamic, context dependent spectrum of conditions. This binary distinction is used in place of a more holistic assessment of the child's needs and the family's capacity to provide appropriate care. Mother-carers share the information they have gathered so that they can help others to understand why their requests may have been denied, and enable them to make a more strategic second attempt at requesting assistance.

Micro-activist affordances theory enables us to see political engagement with the world where other analytical lenses may not detect it (Dokumaci, 2019). Micro-activist affordances "disorient the affordances of an otherwise inhospitable environment", challenging the ableist nature of mainstream structures and spaces (Dokumaci, 2019, p. 516). Unlike campaigns for rights and legal recognition, micro-activist affordances are fleeting and may need to be re-created day after day, but their transience does not detract from their political character. Micro-activist affordances make visible the mismatch between ableist environments and disabled users, demanding to be seen (Dokumaci, 2019). Dokumaci describes the demand made by disabled people through micro-activist affordances as a call for "access intimacy" as defined by Mingus. This refers to the, often unspoken, experience of having one's access needs recognised by another (Mingus 2011, cited in Dokumaci, 2019). Mother-carers negotiate access on behalf of their child and themselves, and they highlighted the importance of engaging with people who 'get it'; usually mother-carers and other people with experience caring for a disabled person. Peer support promotes access intimacy among mother-carers, which can create new possibilities for widening their child's world and possibility of participation.

In addition to enacting small changes, through micro-activism mother-carers can directly resist oppressive systems, becoming "a hair in the flour" (Tsing, 2005, p. 206). Patricia has access to a transport service to take Dalia to medical appointments and therapy sessions. She has to phone the service regularly to book transportation for the coming weeks. One day I was at her house, and we were

discussing the upcoming group discussion, which would be the final one. Patricia told me that she needed to book transport for the next few weeks, and that although it wasn't technically permitted, she would book for the group discussion too. She phoned the service and started dictating dates and addresses to the booking agent. The agent kept asking her to repeat the addresses and explain why they needed to visit each one, and eventually Patricia was put on hold. She was exasperated that they were questioning her about every location even though they have been there many times before. Dalia had therapy three times a week at the same centre, and the group discussions were held at the same venue as the cohort study brigade visits, a health clinic in the south of the city. The transportation service they have been granted is inflexible, and the insurance provider dictates how it should be used. To Patricia, the rule that transport can only be used for therapy is arbitrary and places authority over which kind of activities benefit her daughter in the hands of a faceless entity (insurers and service providers). Patricia takes back power by subverting the service, using it for her purposes and what she deems to be valuable for her and Dalia. As discussed earlier, micro-activist affordances create new possibilities within environments shaped by ableist norms. Mother-carers encounter services that are intended to promote access, and yet are still predicated on ableist assumptions (including curative logics and binary understandings of (in)dependence), or promote paternalism rather than freedom for service users. Dokumaci finds that "disabled people disorient existing affordances of the world in a work of invention" (2019, p. 492), and Patricia's engagement with the transportation service demonstrates that carers also engage create micro-activist affordances through the disorientation of existing resources. Being a "hair in the flour"" means creating "a disturbance of everyday subservience and routine. A hair in the flour ruins the legitimacy of power" (Tsing, 2005, p. 206). The production of micro-activist affordances by mother-carers makes visible the illegitimacy of oppressive and burdensome systems. Having transport is freeing for mother-carers and their children and can create new possibilities for participation (Dokumaci, 2016). However, the restrictive provision of such services is oppressive, as it takes decision making power away from the mother-carer and exposes her to questioning and micro-managing from service providers. Patricia disorientates it by using it as a

means to participate more fully in the research and to have the chance to re-connect with other mothers. In such cases, mother-carers subvert even the services that are intended to increase access for disabled children. Creating a route, space, or possibility in one moment does not guarantee it will remain open, and nonetheless they continue trying, disorientating existing affordances. Mother-carers wish to go beyond fleeting affordances and secure lasting improvements for their children, through more formalised and collaborative activism.

Visible activism and grassroots organising

In the early stages of my data collection, I visited a number of local organisations that supported disabled children and their parents. I wanted to understand what support was available in the non-governmental sector, and whether families affected by CZS were accessing such support through these organisations. I found that most organisations (at least those who remained active after the COVID-19 pandemic) focused on supporting children and young people with particular diagnoses (most commonly Downs syndrome, autism, or physical impairments), or belonging to particular groups (such as university students). The staff and volunteers that I spoke to at these organisations had limited awareness of CZS, and were not aware of their organisations offering support to any families affected by Zika. In turn, none of the mother-carers reported attending events or receiving support form established *fundaciones* or NGOs.

In spite of their limited involvement with existing organisations, the mother-carers did become engaged in some forms of activism before the onset of the COVID-19 pandemic. Hilaria told me that she had gone with Rita and some of the other mothers to a march, to "raise awareness and get them [the local government] to listen to people with disabilities". Julia and Andrea had also attended a protest related to a national campaign demanding monetary renumeration for family carers of disabled people. In addition, the families affected by Zika had come together to form their own *fundación* that functioned as a peer support community and engaged in awareness raising activities. They intended to formalise the organisation and develop more ambitious projects, but the pandemic interrupted

their plans. Ana explained that through the brigade visits, she had observed that the mothers were motivated but lacked the time due to other commitments. She said, "when you speak to them, they tell you they simply don't have time to get together and work on it." Due to public health measures to reduce the spread of COVID-19, and their fear that their children might become infected with the virus, many of the mothers did not see each other in person throughout most of 2020 and 2021. The brigade visit, an event that had previously brought them all together around twice a year, was suspended in 2020 and then severely delayed in 2021.

By the time I started to collect data, COVID-19 vaccines were available and most public health measures had been lifted in Colombia. The brigade visited Barranquilla in October 2022, and I held group discussions with mother-carers in November 2022, and January and February 2023. The aim of these discussions was primarily to allow for participant-led discussion that would introduce topics I had not covered in interviews. Holding in person group discussions also enabled the mother-carers to reconnect and provided a space for them to ask each other questions and share information. Several times, these discussions turned to the re-establishment of the foundation.

Mothers view their micro-activist affordances as essential yet still fleeting and sometimes intangible. They wish to sustain and embed these affordances, widening the world and addressing the absence of resources, information and support in a more systematic way. In other words, they wish to make the society and environment that they, their children, and others like them inhabit, less ableist. They cannot render these affordances permanent on the individual level, but they see the potential to turn these affordances in to further action through the formation of the foundation.

It is important to note that while the mother-carers use the language of disability rights in reference to their child's access health care, education and a good quality of life, they seldom made mention of the right to independent living. I believe this is due to the children's ages, the extent of their impairments, and the relatively limited availability of personal assistance in Colombia. The lens of micro-activist affordances makes visible maternal activism that responds to immediate needs and

may not be precisely aligned with the demands of the broader disability rights movement. Nonetheless, as the children age, it will be important to revisit the topic of independent living in order to understand both the mother-carers evolving perspectives, and if possible, the children's perspectives as well.

Peer support

The topic of re-starting the *fundación* came up several times in individual interviews and group discussions. Mother-carers expressed that they valued spaces of peer support and getting advice from people who had similar experiences. They wanted to capitalise on their shared knowledge and experience by formalising their network into an organisation. Among the mother-carers, Andrea was highly motivated to re-establish the *fundación* for the benefit of all of them. She said "[the *fundación*] will really be a help for those mothers who don't have any help. The mother who is trying, she's looking around, trying to find things out [on her own]." Andrea's statement emphasises the importance of cooperation to improve things in the future. While she imagines an individual mother wondering what to do without any help, she sees the *fundación* as a way to pool knowledge and resources and provide guidance.

Andrea and Rita emerged as natural leaders within group discussions, directing the conversation, asking questions, and giving advice. They both attended the second group discussion, and when the conversation reached a lull, Andrea said to Rita, "since you're here we should talk about the foundation. If we start knocking on doors, we'll make it. As a *fundación* we can take decisive action." They talked about how the *fundación* had been organised before and what they would need to do to formalise a new organisation. Though they both appeared to be motivated to start working on setting up the *fundación*, they didn't make any clear decisions about how to proceed that day. The third and final group discussion was particularly well attended. It was my last time meeting with the families before returning to the UK, and the conversation turned to what would happen once I was gone. Andrea told the group that she wanted to re-start the *fundación*, but was short on time and couldn't do it all by herself. She said "*juntos hacemos más* (together we can do

more), at the moment we are dispersed, and we need people with the disposition and time to commit to the *fundación*". I interpreted her use of the word 'dispersed' to mean that they had been out of touch during the pandemic, and their efforts to organise themselves had faltered as a result. Others in the group voiced their agreement, someone said "yes, if we work together as a foundation it will be easier [to care for the children]".

There were a number of points on which the group did not appear to reach a strong consensus. I summarised parts of the discussion in my fieldnotes. "The next part of the discussion was about who the foundation should be for. Everyone agreed that it would be about children with disabilities, but some seemed more concerned that it should be specifically for children with CZS, while others were less sure or questioned this idea. I didn't get the sense that a consensus was reached on this point." The exact aims of the *fundación* were also yet to be decided. Andrea told the others that in order to register, they would need a mission statement, vision, and objectives. They discussed what the purpose of the foundation would be, and a number of ideas were raised, including helping to gain access to medications and treatments, pooling childcare, and accessing psychological support for mothers[7]. The one point that everyone appeared convinced of was the need to work together in order to achieve greater success in their fight for their children's rights and dignity. While mothers did not like to think about the future as it pertained to their individual family, they found hope in the collective future they imagined through their discussions of the *fundación*.

"If we wait for the state to help us, it will never come"

Andrea also spoke about the *fundación* in an individual interview. She said "I need time, I need to finish my classes. We have to register, do the administration. I want to be involved. Sincerely, if we wait for the state to help us, it will never come". Andreas statement that "if we wait for the state to help us, it will never come" echoes the statement by a participant in Montesi's (2020) research on mutual aid

[7] Since completing data collection I have remained in touch with the participants. As of the time of writing, they have continued to discuss the re-establishment of the *fundación*, but limited time and capacity have stalled their progress towards formalising the organisation.

groups in Oaxaca, Mexico, who said 'if I don't take care of myself, who will?'. The mutual aid groups that Montesi researched were a top-down intervention, whereas Andrea is interested in facilitating bottom-up cooperation to promote wellbeing for mother-carers and their children. Nonetheless, both statements highlight the necessity of cooperation in the face of persisting structural inequalities. For the participants in Montesi's (2020) research, participating in a mutual aid group was part of their everyday "struggle and self-management in the face of societal adversity" (p. 382). This resonates with my participants perspective on their shared future. On an individual level, they envision a future characterised by a continued lack of support combined with the child growing bigger. They have identified self-organisation as a way to address this lack of support. In his work on cooperative businesses, Zitcer highlighted "the extent to which cooperation is a practice of resistance to the injustices of the status quo. That resistance has often been carried out by people who have been marginalized by systems of oppression" (2021, p. ix). For the mother-carers, facing oppression and neglect with their child, working together to form the *fundación* represents an attempt to transform the future for mother-carers as a collective.

The *fundación* represents a potential site of resistance to the interconnected structural forces of ableism and patriarchy. Resistance to structural ableism through mutual aid and self-help is explicit in the group's aims. Women's cooperation in feminist activism (on various causes in addition to explicitly working to further gender equality) also manifest resistance to patriarchy (Chaudhuri and Morash, 2019). This has been observed in Colombia, as Garrido (2019) shows in her analysis of three women's peace organisations. She finds that "in the case of women's organizations in Colombia, through their gender position, they have built subaltern counterpublics that have generated resistance to the established hegemonic discourse" (Garrido, 2019, p. 109). The impact of the *fundación* on mother-carers and their children remains to be seen, and is beyond the scope of this thesis.

While others have analysed organisations of mothers raising children with CZS (primarily in Brazil) and their activism against ableist systems and structures, the

role of gender and manifestation of resistance to gendered oppression is yet to be explored in depth. Further research in this area must consider how mother-carers are shaping the future for themselves and their child, through practices of self-management (as discussed in Chapter 5) and self-help.

Concluding remarks

Theories of lived time have helped me to better understand mother-carers embodied temporal experiences. The non-normative development of children with CZS disrupts 'typical' timeframes for child development, and their caregivers have developed different ways of thinking about time that conform to the child, rather than societal expectations for development and 'progress'. They have adjusted to go at the pace set by the child rather than external demands, pushing back on attempts to normalise their child's developmental trajectory. Using Robertson's theory of "disabled maternal lived time" I have shown how mothers experience temporal interruptions and repetitions in their daily routine with the child. Mothers try not to think too far ahead, but they do have plans for the immediate future, such as gaining access to better therapy or enrolling their child in school. Their work towards these aims is interrupted by delays in access to services and resources, and systems that require them to engage in repetitive processes in order to access basic necessities like nappies. I have advanced Williamson's finding that mothers find it impossible to think about the future owing to the unpredictability of CZS in the context of structural precarity, by showing that ableist, neo-liberal state systems create interruptions and perpetuate the repetitive, gendered care labour of the present and hamper efforts to engagement meaningfully in future planning. Crip time is produced through the intersection of disabled subjectivity, impairment, and ableist social structures, institutions and norms. For my participants, intersectional precarity inflates the influence of ableist structures, further distorting their lived timeline. Societal ableism in the context of broader precarity impairs maternal lived time. Debility is also implicated in mother-carers considerations of the future, as they envision a future in which the present-day lack of support for the and their child persists and their health is degraded by age and the challenges of providing care single handedly. By way of resistance to the structures that impair their

temporalities and debilitate them, mother-carers engage in acts of micro-activism in order to create affordances on behalf of themselves and their child. Based on the way that mother-carers exchange informational resources in order to open up possibilities for them and other families, I have theorised 'mother-carers as affordances', advancing Dokumaci's theory from a feminist perspective. I have also shown that mother-carers wish to sustain and embed the affordances they have created through the re-establishment of a grassroots organisation of mother-carers. They found hope in the collective future they imagined through their discussions of the *fundación*. At the time of writing, this remains as a collective imaginary, and warrants further research. In this way, the future is both the subject and the orientation of this final empirical chapter.

PART IV: CONCLUSIONS

Chapter 8: Conclusions

In this thesis, I set out to explore the intersection of patriarchy and ableism in the lives of mothers raising children with Congenital Zika Syndrome. It is apparent that each of these sets of structural forces has a profound impact on the mothers and their children, and that the intersection of these structures produces a distinct and more abject set of challenges. The theory of intersectionality posits that individuals who occupy the intersection of multiple axes of social oppression experience a distinct and often amplified form of oppression beyond an additive effect (Hill Collins, 2000). Here I argue that the mothers gendered social position and the child's disabled one intersect to produce a unique form of disadvantage that impacts them both. This is mediated through the close relationship of care, which is central to this thesis. I have found that the concentration of care for children with CZS with their mothers is mediated by the patriarchal division of labour, ableist health and education policies, and familist disability policy. Together with the affective bond between mothers and their children, these structures produce a close relationship of care in which mother-carers and their children spend most of their waking hours together and navigate the world side by side.

While it is apparent that structural factors have a profound impact on the lives of the participants, mother-carers agency has nonetheless emerged as a central theme of this work. Agency is central to mother-carers health system navigation and practices of *autoatención*. I distinguish purposefully between agency and resilience. Mother-carers respond to and overcome barriers and neglect, but they do not accept this status quo. Rather, they maintain the belief that systems and services can and should be made accessible and supportive to themselves and their children. They engage in peer support and activism in the hopes of reaching this end.

Underpinning their rejection of the ableist status quo is a political stance on disability, identifying external discrimination as the source of at least some of the challenges they face with their child. Further to this, mother-carers themselves experience disability discrimination by association. These experiences of

discrimination represent a manifestation of structural violence, which has shaped the mother-carers relationships to the institution of motherhood.

Contribution to knowledge

Through a critical synthesis of the existing literature, I identified a number of areas where I could build on the existing empirical and theoretical knowledge base. This review informed the research questions guiding this thesis. The contributions to knowledge in relation to each of these questions is discussed below.

How does the intersection of patriarchy with ableism shape the experience of caring for a child with Congenital Zika Syndrome and the parental role?

A review of the extant literature confirms that the impact of the 2015 – 2018 Zika epidemic and its aftermath was profoundly gendered. Intersecting structural vulnerabilities on the basis of gender, race, age, socio-economic status, and location have compounded the disproportionate impact of the virus, concentrating the most serious outcomes among the most marginalised populations.

A synthesis of the literature demonstrates that gendered inequalities underpin restrictions on reproductive autonomy, which in turn further entrench those inequalities. The gendered division of reproductive labour is a focus in the literature, as is the social construction of motherhood, however the interaction between them has not been explored in much depth. Furthermore, the role of societal ableism against the child has not been explored in relation to these areas. I have addressed these gaps in my thesis.

Societal ableism is underpinned by the coloniality of being and results in the perpetuation of structural violence against disabled children. Children with CZS are dehumanised by the state on the basis of their impairment, which from a medical deficit perspective, makes them less productive or 'effective' future citizens (Mack, 2018). This dehumanisation, a manifestation of the coloniality of being, leads to the neglect of disabled people and violations of their rights by the state. Due to the patriarchal division of labour, it is mothers who confront this discrimination and neglect on behalf of their child. Other authors have shown how structural violence

re-shapes motherhood from a private, personal identity to a public, political role. In the context of CZS, this has been discussed primarily in relation to mother-carers' formation of grassroots activist groups in Brazil. I have shown how mother-carers politicisation of their role is not exclusive to their participation in visible forms of political activism, and is evident in the way they approach care itself. I have shown that mother-carers reconceptualise their role in the face of structural violence against herself and her child, and make demands of the state to provide services and resources that would alleviate the pressure on them as the primary caregiver to a child with CZS. Rather than striving to be 'good mothers', participants demand 'good care' for their child. By making an outward demand for 'good care' provided by the state and other caregivers, they assert their child's personhood in the public sphere. I have extended Williamson's (2024) finding that mothers' investment in habilitative care represents an assertion of personhood, showing that the politicisation of motherhood moves the role into the public sphere, and thus the assertion of personhood takes place also in the public sphere. I have furthered Runswick-Cole and Ryan's conceptualization of 'unmothering' by bringing their theory into dialogue with theorisations of political motherhood and marginal mothering in Latin America. I have developed the theory of 'unmothering' from the margins to describe the politicisation of motherhood in the context of the particular precarity faced by low-income mother-carers in the Global South.

One of the ways that mother-carers reconceptualise their role is through a rejection of the notion that care is unidirectional. Mother-carers see their wellbeing as intertwined with that of their child and highlight that state neglect of the child has negative health effects for their caregivers. In light of this, I have shown the lack of appropriate support for disabled children is debilitating to both the children themselves and their carers. Williamson and colleagues (2023) have shown that enabling a disabled person without adequate support can be disabling to the caregiver. I have extended this analysis by bringing together debility with interembodiment, finding that neglect of disabled people can also lead to interembodied debilitation of themselves and their caregiver. The finding that neo-liberal, ableist health and welfare systems intersect with patriarchy and the gendered division of labour to impair caregivers puts the onus back on the state to

enact more equitable policies that protect disabled people and their caregivers. This also offers a rebuttal to the notion that it is the child's condition or impairment that burdens the caregiver, again highlighting that the true burden emanates from the intersection of patriarchy and ableism at the level of the family unit.

What barriers to accessing healthcare and education do children with CZS face, and how do their caregivers respond to these barriers?

Existing literature has shown than children with CZS face numerous forms of discrimination, ranging from social and economic barriers to full participation to the stigmatising remarks of family, friends and neighbours. Discrimination is built into health and education systems, with the result that children with CZS experience numerous barriers to the full enjoyment of their rights. It is apparent in the literature that family caregivers, primarily mothers, expend considerable time and effort trying to overcome these barriers. I have added to this by highlighting the particular burden imposed on caregivers by long delays in granting requests for services and resources, and requirements that mother-carers regularly re-submit requests for resources their children need long term (like nappies). In the existing literature, the strategies they use to overcome barriers to accessing health services have received limited attention. I have addressed this gap, illuminating the diverse strategies that mother-carers use to navigate exclusionary systems and negotiate access to care and resources on behalf of their children. Bringing together cultural health capital with *autoatención* has enabled me to highlight the role of agency in health system navigation in the face of exclusion. I have shown that mother-carers are the nucleus of the health-care-treatment process, and that they reconstitute existing health care resources in order to create access. I have shown how participating in spaces where experiential knowledge is valued has empowered mother-carers as epistemic agents. This has enabled them to generate new knowledge about CZS and refine practices of *autoatención* on behalf of their children.

Mother-carers engage in acts of micro-activism in order to create affordances on behalf of themselves and their child. I have extended Dokumaci's theory of 'people

as affordances' to show that in the context of gendered care work, 'mother-carers as affordances' create the potentiality for greater access and inclusion for their child and themselves together. They exchange informational resources in order to open up possibilities for them and other families. They wish to sustain and embed the affordances they have created through the re-establishment of a grassroots organisation of mother-carers. Mother-carers found hope in the collective future they imagined through their discussions of the *fundación*. At the time of writing, this remains as a collective imaginary, and warrants further research.

In this thesis, the distinction between independence through paid personal assistance and care within the family has not been addressed in depth. The reality for the families involved in this research is that professional assistance is mostly out of reach owing to their enrolment in the subsidised health insurance scheme, or for some, not having health insurance. In some cases, the mother-carers expressed uncertainty about the ability of paid care assistants (whom they mostly refer to as nurses) to adequately support their child (as discussed in Chapter 4). The children in this research receive both care and assistance from family members, primarily their mothers. For the small number of families who have access to professional care, this is managed by the primary caregiver, who instructs the care assistant on how to look after the child, and sets the terms of the relationship. Mother-carers are invested in facilitating the development of a rapport between the child and any professional care assistant. They work with the care assistant to ensure that the child receives good quality care from them together (this dynamic is described in Chapter 4). The autonomy and independence afforded to the mother by the provision of paid care assistance is more readily apparent in this case study than that afforded to the child. None of the mother-carers interviewed discussed the possibility of their child living independently from them with support from personal assistants in the future. This may be because the children are still young, aged between 5 and 7 years old at the time of the data collection, and at that age children are expected to depend on their caregivers to fulfil their basic needs. It may also stem from the fact that such a life is unfamiliar to the women in this research. The mother-carers often shared anecdotes with me about other disabled people they knew, both children and adults, and what they had learned from their interactions

with them. To my knowledge, none of the mother-carers counted among their acquaintances a disabled adult or older adolescent who live independently with support from personal assistants. As a result of these factors, the mother-carers in this research imagine a future in which their child will continue to depend on them for personal care into adulthood (as discussed in chapter 7). It is likely that they will continue to seek out paid care assistance, and that barriers to access will persist. The possibility of independence through personal assistance should be re-visited in future research as the children with CZS get older.

How do parents of children with Congenital Zika Syndrome understand their child's condition and conceptualise disability?

In the majority of the qualitative literature on Congenital Zika Syndrome, disability is implicitly framed or explicitly understood as the interaction between an individual's bodily or cognitive function and the social, political, economic and legal environment they exist within, in line with the social model of disability. A smaller number of authors have used and developed critical theory in order to better explain what disability means and how it is constructed in the specific case of CZS.

In this thesis, I have shown that a social-interactional model of disability underpins mother-carers interpretations of their child's condition. In clinical settings, professionals appear to view the children's condition through a medicalised lens. This is evident in the way they are evaluated against standardised development markers that presume a typical, linear process of child development. Mother-carers actively engage with the medical system on behalf of their children, but push back against this conceptual medicalisation. They have developed counter-narratives to the dominant medical framing; that their child goes at their own pace, is disabled, not sick, and that their children are a source of joy, not a burden. In doing so, they reject the notion that their child has a deficit or flaw. Rather, they identify discriminatory attitudes, social barriers, and a lack of opportunities as the source of their child's exclusion from full participation and enjoyment of the rights to health, education and a dignified life.

However, the social model alone is not able to fully capture their conceptualisation of disability. The distinction between impairment and disability is central to the social model of disability. The mother-carers understand disability as a way of being and point to the similarity, rather than the difference, between impaired and unimpaired people. The social model has been criticised for placing outsized importance on social barriers and neglecting embodiment (Kafer, 2013a). In line with this critique, the mother-carers in this research highlight the harms of impairment itself, such as pain and discomfort, that cannot be undone by the removal of social barriers. Finally, the social model includes a demand for the removal of barriers to independent living for people with impairments. This has been criticised for overlooking the experiences of people with more complex and profound impairments who would require care and support even if social barriers were removed. The mother-carers in this research recognise that their children will need lifelong care, and rather than striving for independence, highlight the interdependence between the caregiver and the person being cared for.

In the process of conducting this research and analysis, I came to understand that mother-carers not only understand disability, but experience it themselves in an embodied way. Mother-carers experience discrimination by association, which limits their own participation and enjoyment of their rights. Further to this, they are also debilitated by the same set of social conditions that disable their child. Goodley, Lawthom and Runswick-Cole (2014) have brought the concept of debility directly into dialogue with current debates in critical disability studies, and Williamson, Engel and Fietz (2023) have directly applied the concept to caregivers of children with CZS and other disabled relatives in Brazil. I extend these analyses by bringing together debility and interembodiment, showing that the lack of support for mother-carers and their children results in conditions of daily life that threaten to further debilitate their children, and necessitate a mentally and physically debilitating routine of daily care. I have referred to this process as interembodied debility.

Beyond the embodied experience, discrimination by association impairs mother-carers experience of time. I have shown that health and education systems create

repetitions and interruptions for mothers, through the requirement that they repeatedly re-apply for the same services, and the long delays that occur before any decision is made or access to resources granted. These repetitions and interruptions preclude mother-carers from making progress towards larger goals. In this way I have extended the theory of crip time, finding that societal ableism in the context of broader precarity impairs maternal lived time. I have found that involvement in grassroots organisations may offer the potential for a more collective orientation towards the future. The development and impact of such an organisation in this context warrants further research.

Implications

Locating the source of 'burden'

Disabled children are often portrayed as a burden on both their parents and the state (Ryan and Runswick-Cole, 2008). This thesis offers a counterargument to these ideas by turning the focus on to the burden placed upon disabled children and their caregivers by the state. The privatisation of care to the family unit places a high burden on caregivers, who are forced to pass up work, education and leisure opportunities in order to care for the child. The denial of services creates extra work for caregivers, which can be mentally and physically debilitating to them. Together, these circumstances can cause a deterioration of the child's condition in spite of the caregivers' best efforts. Together with the recent recognition by the UN CRPD (2022), that parents of disabled children experience disability discrimination by association, this represents an important opportunity to re-frame how we think about disabled children and the role of the state. This work highlights the political production of disability and the interdependence between caregivers and the people they care for. By elaborating on the interembodiment of disability discrimination, I have shown that the very meaning of disability in this context is bound up with patriarchy, familism, precarity, and poverty.

Understanding parents' behaviour

In their interactions with service providers, parents of disabled children are sometimes derided as either passive and fatalistic, or overly aggressive (Colker, 2015). Such characterisations tend to be used to blame parents for their child's challenges, diverting attention from the lack of service provision (Colker, 2015). I have offered interpretations that can help to better understand parents' behaviour in the context of inadequate service provision. In order to directly self-manage their child's health, mother-carers move between formal and informal spaces of care, bringing them into contact and reconstituting them in order to provide their child with care. In doing so, they fundamentally alter the resources and services themselves. Mother-carers living within financial and time constraints may not engage in behaviours that are outwardly legible as activism, such as creating petitions or going on marches. Furthermore, the demands of the mainstream disability rights movement may not resonate with mother-carers based on their social position. On one hand, they occupy the position of able-bodied caregivers. On the other, they experience the embodied debilitating effects of disability discrimination and societal ableism by association. Using the lens of micro-activism reveals the political character of mother-carers behaviour, contributing to the theorisation of 'mother-carers as affordances'. These findings highlight the important of deeply engaged ethnographic research that can illuminate an individual's motivations and help explain their behaviour.

'Unmothering' in the Anthropocene

My theorisation of 'unmothering' from the margins emphasises the role of state violence and neglect in harming populations and producing disability. This theoretical contribution is relevant to other forms of 'atypical' motherhood, where caregivers confront state violence, discrimination and neglect directed at their children. The present convergence of environmental destruction, anthropogenic climate change, and attacks on reproductive autonomy are likely to increase these forms of harm against children. Parents ability to raise children in safe and healthy environments is threatened by environmental degradation and climate change.

Disabled children living in precarious circumstances are particularly vulnerable to disasters, and preparedness, mitigation and response efforts may overlook their particular needs (Peek and Stough, 2010; Ronoh, Gaillard and Marlowe, 2015). Anthropogenic climate change is expected to increase exposure to agents that can harm foetal health, which will cause increased rates of congenital impairment (Dadvand, 2017; Haghighi et al., 2021; Ha, 2022). Limits on reproductive autonomy, such the criminalisation and punishment of abortion, disproportionately affect those with the least resources (Whelan, 2023). Combined with stratified exposure to harmful agents in the environment, this leads to the concentration of congenital impairment within marginalised populations (Bridges, 2022). These factors are likely to precipitate the politicisation of mothers and a reconceptualization of the maternal role, which may be understood through my theorisation of 'unmothering' from the margins.

Directions for future research

A key strength of this thesis, the in-depth engagement with mother-carers, also reveals a limitation in that the children's perspectives are not explored. At present, their ability to communicate is limited by their impairments, and they are very young. It is not known how they will develop and what might be possible in the future. As they grow, it will be important to seek their views and perspectives on the barriers they face, how their care is managed and what kind of resources they need access to in order to achieve a good quality of life.

Owing to gaps in policy and implementation, independence through personal assistance for disabled people in Colombia remains under-explored. Some of the mother-carers in this research have had success in securing access to professional support, which the mother-carers themselves direct and manage owing to the children's young age. Further research could explore how this assistance is managed in the future and the impact on the child and their family as the children grow up and their mothers continue to age.

Finally, the re-establishment of the mother-carers *fundación* invites further research. The vision, mission and objectives for this *fundación* are yet to be

established and may be revealing in terms of the current needs and demands of the mother-carers and their children. Future actions of the organisation may further illuminate the mother-carers political stance towards disability, care and assistance.

Final remarks

The Zika virus epidemic of 2015 - 2018 garnered substantial international attention, but this interest quickly faded once it became apparent that the epidemic would remain localised to Latin America and the Caribbean. The long-term consequences of Congenital Zika Syndrome have similarly faded from public attention. However, for the families affected, CZS has become a defining feature in their lives. I hope that in producing this ethnographic account, I have been able to make a small contribution to ensuring that the lasting impacts of Zika are not forgotten and the people affected by CZS are not left behind. As discussed, I returned to Colombia around 6 months after completing data collection to share my initial findings with the staff of the INS cohort study. They intend to use this evidence to support the mobilisation of additional resources to support these families and others affected by CZS.

Since the inception of this project, the world has faced numerous public health emergencies driven by known and emerging infectious diseases (Wilder-Smith and Osman, 2020; Zardi and Chello, 2022). As I write these final remarks, news is emerging about outbreaks of Oropouche virus across South America (Ministério da Saúde, Brasil, 2024). Two deaths have been reported, and preliminary reports suggest that infection during pregnancy may cause microcephaly and pregnancy loss (The Lancet Infectious Diseases, 2024). Climate change and environmental destruction are likely driving these outbreaks in areas where the virus has not previously been endemic (LSHTM, 2024). Research on the health impacts of climate change has also brought renewed attention to the Zika virus, as increasing temperatures are predicted lead to the expansion of the range of the mosquito vector (Ryan et al., 2019). Future outbreaks of neglected and emerging diseases are likely to have a disproportionate impact on poor and marginalised groups (Farmer,

2016; Bambra, 2022). The COVID-19 pandemic has fuelled growing rates of inequality in the continent (Acevedo et al., 2024). The response to emerging infectious diseases must be grounded in principles of social justice, and as new outbreaks make headlines, it is imperative that those left in the wake of prior epidemics are not forgotten.

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