Planning for the Margins: Mapping Conceptual Implications of Profound Intellectual Disability and Informality through Slovo Park, Johannesburg

by

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Abstract

Disability remains one of the most marginalized considerations within urban planning and social justice research and practice. Disability affords planning the critical conceptual lens of interdependence, moving beyond ideas of individualized independence. Interdependence is an especially salient provocation for how we live in today's world, shaped by COVID-19 and global crises brought on by climate change, meaningful work and livable wages, generative AI, and future pandemics. This thesis focuses on the challenges of urban planning for and with people with profound and intellectual disabilities in informal and impoverished Global South contexts as an acute, but nonetheless pervasive, example of the need and precarity of interdependence. Drawing primarily from fieldwork in the informal settlement of Slovo Park, Johannesburg, this thesis aims to calibrate what it means to "plan for the margins" in situations of compounded vulnerability and resource scarcity. In doing so, it documents vitally important kin and care networks existentially challenged by neoliberal market forces. It argues that profound disability ought to be a central planning concern, informing how we transform social relations and build infrastructures of care that center deep vulnerability.

Thesis Supervisor: Delia Wendel
Title: Assistant Professor of Urban Studies and International Development

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For Hammad and Phupho

There is no fault
With a mad person
The fault lies in you-
Love hasn't maddened you yet[1]

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[1] Attributed to Sarmad Kashani c. 17th Century. Sarmad Kashani was a renowned mystic and poet in the Subcontinent, born originally in Safavid Armenia. He renounced material attachments and was often found wandering naked in the streets of Delhi. He was executed on charges of heresy by orders of Mughal Emperor Aurangzeb in 1661 (Prigarina 2012).

Introduction

Fieldwork for this thesis was carried out in Slovo Park, an informal settlement located on the outskirts of Johannesburg, South Africa, over the summer months of 2022 and winter months of 2023.[2] Methodologically, a litany of insights and challenges came to the forefront in terms of trying to include people with profound disabilities as the population of interest for conventional qualitative and ethnographic methods, which I elaborate on in Chapter 3. However, at the heart of it remained one particular case – Cara's[3] case, which epitomized the extraordinary precarity and impossibility of choices that can manifest when a profoundly disabled body meets a profoundly disabled environment, so to speak.

> Please take her away from here, if you can (Interview with Daniella, Slovo Park, Johannesburg, July 17th 2022).

Cara is a twenty-year-old girl with cerebral palsy (CP), resulting in an intellectual age of approximately a four-year-old. These words, by Daniella, Cara's mother to me, have stayed with me during the course of this research, and which is why I think they are also necessary to begin this thesis with. What kinds of planning processes have led us to arrive at this moment, where somebody is readily willing to give up their child to a stranger because they, perhaps, feel finally heard by them? Why do they have to choose between caring and protecting versus providing for their child?

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[2] Summer and winter months as associated with the Northern Hemisphere. I faced the converse at the destination of my visits.

[3] Names changed to protect privacy.

0.1 A Glossary

Before moving forward, a glossary condensing some concepts, as I deploy them in the thesis, is provided. While these concepts are explained in-text too, they are, out of a need, sometimes invoked preceding their explanation therein, and so a baseline at this stage is gathered here for aid and organizational purposes.

Term	**Definition**
Ableism	Prejudice faced by disabled people. Hamraie (2021) also defines ableism as a structure that works by privileging some disabled people's needs (e.g., those of wealthy, white, straight, non-profoundly disabled) over others.
Disability	As defined by the social model, disability is produced by social and environmental factors. It situates environments and social stigma as the location of “fix” – as opposed to a medical model, which focuses on the body as the site in need of correction.
Disability Justice	A critical, intersectional framework that names the interdependence of disability oppression with other oppressive systems/structures and advocates for the urgency of centering anti-ableist practices and values in broader movements for collective liberation (Shelton 2021). It also means a commitment to not leaving any disabled people behind (Hamraie 2021).
Disability Planning	Disability planning as a necessary conceptual proposition for the discipline, one that invariably leads to changes in normative values and ethical reorientations, guided through planning instrumentally, as we prepare and adapt for various kinds of future crises.
Intersectionality	Intersectionality is a social justice idea that casts critical attention to the ways in which different identities, social locations, and systems of power interlock with and shape each other. It asserts the principle that “nobody's free until all of us are free,” and this freedom depends on creating the space and opportunity for all people to be recognized, valued, protected, and supported—without exceptions or conditions.

Planning for the Margins (PFM)	A concept that proposes that by planning for the most marginalized, we ultimately plan for everyone, including the majority (McDowell 2015).
Profound Intellectual Disability (PID)	Any disability where informed consent is not possible. Profound disabilities refer to severe impairments that significantly impact an individual's cognitive and physical functioning, rendering them unable to fully participate in decision-making processes or articulating their needs and preferences in traditional ways.

0.2 The Future is Disabled[4]

Would the COVID-19 pandemic have transpired, as catastrophically as it did, if we had planned for all scales of disability? This is a simplistic provocation, but looking past the absolutism, I think it is a viscerally useful[5] [6] way to begin framing disability and its most aspirational affordances and implications for planning, at this particular moment, especially at this particular institution (DUSP MIT), and with my particular positionality. Afterall, the pandemic has served as a "mass-disabling" event - uncontainably universalizing experiences of immobility at its peak in 2020; and since then, leading to a variety of disabilities and chronic illnesses which we are still beginning to witness unfold due to long COVID. Many in the disability community continue to assert that if we had meaningfully planned for disability, the pandemic wouldn't have been as destructive to the degree we witnessed, at least not the infuriating scales (and, very much, constructs) of the lives versus livelihoods "quandary" we had

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[4] Borrowing the title from Leah Lakshmi Piepzna-Samarasinha's (2022) book.

[5] I could start this thesis with static statistics about world population estimates about disability, but I intentionally resist the impulse to do so, because disability is an identity umbrella which anybody can find themselves under, at any point in their lives. It is not necessarily a stable or unified category or quantity, and can shape-shift overnight (as the pandemic has reasserted). It is therefore a disservice to try to restrict its intellectual dynamism and affordances solely towards a distant, distilled, disparate/"boxed" and therefore otherized segment of the human population.

[6] I understand this can invoke a "utilitarian" framing of disability-justice perspectives for planning, which reproduces a logic that disability perhaps fundamentally unravels, but since planning is a profession and a discipline, my motivations are a means. I discuss utilitarianism and disability more in Chapter 1.

to come to grips with. But that would also mean planning for and imagining a remarkably different kind of world, with different priorities, values and *pace* undergirding its political, economic and governance systems and bequests. One where disablement, through carceral practices and immobility, is not socially constructed and reproduced as the ultimate form of punishment, second only to death. Also, one, where global and globalized processes of exchange being halted or "disabled" by the pandemic, would have been entirely anticipated and accounted for, without leading to the insurmountable anguish, isolation and death that we invariably experienced. Leah Lakshmi in her new book, titularly asserts that *The Future is Disabled* (2022), given current resonance and relevance of disability justice concepts of interdependence, vulnerability and care. Within the disability community, this moment is seen as a galvanizing one that inextricably ties everyone's well-being to the well-being of disabled people. Yet curiously, but unsurprisingly, the disability question for planning still continues to be disregarded from planning resources aimed at understanding the implications of the COVID-19 pandemic through a spatial inequality and justice lens, despite instinctively being the most spatial of social justice issues.[7]

0.3 Blind Spots in Urban Planning Pedagogy and Practice

Sara Hendren terms this academic blind-spot and knee-jerk hesitation an "intellectual ejector seat," something which I, as somebody with lived familial experiences with profound disability, had to acutely confront in the first semester of my MCP degree at DUSP MIT. In the recitation[8] for my Gateway class's session on disability, the reflections of my peers were

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[7] For example, see "Pandemic Urbanism: Praxis in the Time of Covid-19" (2020). A quick search for "disability" in the 52-page document yielded zero results.

[8] Recitations are smaller discussion sections for large lecture classes at MIT.

unsettling to hear. The terms “impossible,” and “unfeasible” when discussing the practicality of including the spectrum of disabilities in planning design or policy, were posited with considerable ease. I doubt that my peers would have felt parenthetically as comfortable articulating similarly for social justice issues with perhaps more currency. That semester I also approached several faculty at the department with an invitation to supervise an independent study on disability which proved to be a significant challenge. A surprising number turned my proposal down, reflexively asserting it was not their area of expertise or an issue that they have had much familiarity with – even though this was fundamentally an invitation to collectively expand and deepen mutual analyses and scope. I did eventually find support in two extremely encouraging and caring professors[9] for whom this has also entailed reaching beyond their areas of expertise, but nevertheless the process was indicative about how disability is received as an issue that immediately strikes as foreign and impalpable and how these sensibilities and encounters also need to be acknowledged and unpacked in order to be redressed.

Planning, especially progressive forms of planning, aims to ex-ante contend with issues of the built environment and social justice. Under the ambit of planning for the public interest, the discipline has a responsibility towards thinking from the forefront in terms of environmental and social issues concerning disability i.e., the social model of disability.[10] Within this specific discipline, especially, there is scope to develop toolkits that can offer practices and approaches that represent a preemptive commitment to disability, instead of treating it as an afterthought or a retrofit project, as has historically been the usual case. Conversely, disability as a generative

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[9] I am immensely indebted to professors Delia Wendel and Mariana Arcaya, for not only creating so much space for my ideas, but also for being in-team and taking proactive ownership of the Disability Justice and Planning Initiative at DUSP MIT with me and my classmate and collaborator Shannon Hasenfratz.

[10] The social model of disability situates environments and social stigma as the location of “fix” – as opposed to a medical model, which focuses on the body as the site in need of correction.

inquiry, can advance planning discourses, through and beyond design, by fundamentally reconceptualizing undervalued care, productivity and normativity – all foundational themes which underpin social justice planning agendas and issues.

I bring my own yardstick to the table in terms of disability. My twenty-four-year-old brother with cerebral palsy and microcephaly passed away in 2020, in Karachi, after a prolonged and slow decline in his health. The language of "reasonable accommodations" I have found to be largely alienating and inapplicable to my brother's case, because of the nature of his profound disabilities. Beyond accessible infrastructure, acute and profound disability requires a contention with underlying value systems that individualize autonomy and agency. Centering impoverished localities with no safety-nets, which have to, nevertheless, deal with pervasive neoliberal market forces that erode valuable preexisting kinship support networks, is thus important. Through this thesis, I begin to theoretically make a case for why the "planning for the margins" framework is suited to consider profound disability – in particular, persons with nonverbal and intellectual disabilities who cannot advocate for themselves – as a starting point. Attention to this critical positionality draws planners' focus to intersectional needs especially in resource-scarce contexts of informality; situations often conceptually rendered as "unplannable." In doing so, I make a case for the important theoretical potential at stake for the discipline too, if it chooses to proactively consider the needs for this complex, but propounding, corporeality.

This thesis is an attempt to formally practice writing about disability and verbalizing the complexities for which language or communication models were not accessible through the course of my educational or professional trajectory (even within planning school, where I was expecting them to be). It is also the first time I am practicing writing about a context in which I cannot claim any sense of belonging as yet. It is also an exercise in being responsible with stories not my own, and staying attentive to privilege and lop-sided social dynamics embedded in this operational method of ethnographic research; where I have considerably more agency and ability to control narratives which belong to somebody else – but not necessarily claims to full insight yet. It is thus descriptive, intentionally as unassuming as possible, and very far from complete or cohesive in its assertions of what all experiences with profound disability in "the Global South" can entail. It attempts to cast light on some modes of existence that are rendered entirely invisible from every day and normative imaginations about urban life. It very much is my representation of the lives of others, informed by my lived experience and relational proximity to profound disability in a highly stratified urban setting, but also constrained by my limits as an outsider on many fronts, including region, economics, disability and motherhood. It is also an extremely challenging endeavor, given that it aims to be a call to more embodied treatment of disability justice in policy, at a time when my own position in my trajectory of loss, and its ensuing baggage of disembodiment and disassociation is still felt.

It is structured so that in addition to a research account from fieldwork in Johannesburg, it is interspersed, as necessary, with "misfit" encounters of studying city planning at MIT – an institution where there is probably the most premium placed on achievement, ability and capacity – from the lens of my experiences growing up with my brother Hammad in Karachi.[11]

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[11] I think of this as attempting to emulate what feminist theorist Karen Barad calls a "diffractive reading," which she describes as a method of "reading insights through one another in ways that help illuminate differences as they emerge" (Barad 2007, 30).

Chapter 1: Considerations for Disability Planning

"Failures of preparedness can produce impossible moral choices"[12]

Disability as a frame of analysis has largely been absent from the discipline of planning. Existing scholarship on planning and disability is nascent and limited. A 2021 review of five prominent planning journals since circulation yielded only 36 journal articles referencing disability from a total of 1107 issues, of which only 20 focused on disability as a central topic (Terashima and Clark 2021). All 36 studies are from countries associated with the Global North. Emerging scholarship on disability and planning, recognizes how the pandemic has revealed the fragility of systems of mobility, relationality and care (Stafford, Vanik and Bates 2022). This chapter makes a conceptual case for centering disability in planning by firstly recognizing how the recent pandemic, especially, has upended and rendered moot hard cases for utilitarianism and techno-rational planning and problem-solving derived from it; and connects this to tacit eugenicist implications in utilitarian approaches, such as the rise in non-invasive prenatal testing (NIPT), that incentivize "erasing/fixing" disability,[13] calling instead for more expansive building blocks undergirding planning theory that can center, and aspire towards *valuing* dependencies and interdependencies. It next connects David Harvey's (2008) conceptions of Lefebvre's traditional right to the city framework with the social model of disability, indicating how the traditional "cry and demand" slogan, and presumed reliance on social reproduction to guide and shape progress and inclusion through resistance, also assumes certain abilities and capacities for self-advocacy. It does so by acknowledging the limits of an individualized rights-based assimilation approach as an end of itself, when thinking about profound disabilities. It then notes

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[12] (Pascoe and Striplong 2020, 423)

[13] Or, paradoxically, by creating "pitiable" disability, as this thesis later demonstrates.

the importance of transitioning to a justice model of disability and the importance of tying that in with a planning for the margins (PFM) framework with profound cognitive disabilities in mind; and the transformational and generative conceptual opportunity that is engendered for planning, especially as the discipline orients towards addressing the climate crisis, future pandemics and universal implications for work with the advent of AI.

1.1 Limits of Utilitarianism

I recently came across international development discourse taught by Nobel laureates at MIT's economics department on the merits of intentionally making provision of unconditional cash-transfers (under the ambit of social services) more difficult, in order to ensure "target" accuracy. As I juxtapose this with Cara's case from my fieldwork in Johannesburg for this thesis, or my own lived experience with disability in Karachi, this scarcity-minded approach to "problem-solving" installs precarity and anguish, by restricting and making access to welfare even more moot. It represents an administrative and institutional stagnation which planning and development conceptual frameworks, especially those geared towards resource-scare localities with disability in mind, need to update.

It is with this motivation I would like to highlight some limits of utilitarianism-derived-rational approaches to development and the attendant technocratic methodologies, which planning endeavors often rely on – first through the pandemic to express universality of vulnerability. And then match and map these critiques directly with preexisting and long-standing expostulations of utilitarianism within disability studies. And in the process, I will construct a case for the importance of subordinating a scarcity-mindset which entrenches utilitarianism, to one which envisions and aspires towards abundance`(Fujikane 2021) and recognizes human beings as “vulnerable vectors" (Pascoe and Striplong 2020, 433) embedded within networks of interdependence, and (dare I say), dependence. Through this framing, I hope to suggest a planning agenda and roadmap for our environmental future, based on disability justice, that meaningfully accounts and prepares for all scales of vulnerability that are socially reproduced (Harvey 1985), recognizing them as both, imminent and immanent, to processes of global capitalism and its spatial and material loci i.e. cities and urban centers.

At the beginning of the pandemic, the ethical conundrum of ventilator shortages and policy discussions that framed the question of "lives versus livelihoods" as a binary dilemma were urgent issues that drew on utilitarianism as the “rational” and “pragmatic” solution, leading directly to rankings about the worthiness of lives. According to Pascoe and Striplong:

> This turn tracks our moral intuitions that in times of great scarcity and competition, sacrifices will be necessary, and because they will be necessary, they will be acceptable. These choices are well-intentioned but infected by underlying biases and an “elite panic” that disasters will cause society to descend into a chaotic state of nature: the history of disasters teaches that these events overwhelmingly exacerbate underlying inequities and that governmental responses tend to reinforce those inequities, not improve them. (Pascoe and Striplong 2020, 420)

They further note that these principles can historically be traced to emerge from values undergirding militarization and wartime arbitrage:

> As COVID-19 threatened to overwhelm Italy’s healthcare system, fear of scarcity took hold. A clinical association issued guidelines for how to allocate increasingly scarce medical resources. They told doctors to prioritize those “with a greater likelihood of survival, and second, who have more years of life left” for ventilators, “in order to maximize the benefits for the largest number of people.” Doctors involved in developing the guidelines called them “soft utilitarian” principles and justified the choice as consistent with wartime triage and medical ethics in a catastrophe. (Pascoe and Striplong 2020, 420)

In addition to revealing the fragilities of the global care and health infrastructure (Goodley et al. 2021), the pandemic also drove home the parochialism of governance and economic priorities shaping it. It bodes wonder, if planning and governing bodies had meaningfully planned for disability, at its most acute scales, we may have had more robust systems and mechanisms in place, based not only on care and other-regard, but ones which also valued it. This would potentially have limited the more catastrophic consequences of the pandemic on a moral and material level – where we saw traditional medical ethics of prioritizing emergencies and people with the greatest immediate need,[14] to the inverse – where instead those who had the most likelihood to survive were prioritized. According to Stafford et al. (2022), the gendered split at the start of the twentieth century between social work and urban planning resulted in disabled people's expertise being funneled into helping professions, such as social-work, instead of urban planning. Despite the pandemic serving as an indictment, certain discourses by ethicists and utilitarian philosophers (Savulescu et al. 2020, Buck 2020) continue to pose utilitarianism, and the ranking of human worthiness, as a rational pathway and response to the pandemic and disaster management strategizing; when in its premise of utilitarianism as a planning building block, and a technocratic rationality emergent from it, is in fact what arguably led to its more disastrous consequences. This rationality premises temporal and material efficiency based on mechanisms that institutionalize and entrench fear and precarity as desirable instruments for incentive structures and design mechanisms (Neilson 2015). And this form of efficiency structure informs and leads to value-laden and normative ideas about "factual circumstances that are inherently unreasonable" (Weibgen 2015; pg 2417).

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[14] An existing social organizing logic that ties in with planning for the margins was discarded in the face of a society-wide crisis.

Before transitioning to disability as a conceptual lens for the post-pandemic moment, and conceptually framing disability as a generative inquiry for planning, I think it is useful to invoke two assertions by planning theorists:

> Defining reality by defining rationality is a principal means by which power exerts itself. (Flyvberg 1998, 319)
>
> Large-scale social change typically occurs as a result of a unique constellation of highly disparate events and is therefore amenable to paradigmatic thinking only in a very special sense. The initial effort to understand reality will almost inevitably make it appear more solidly entrenched than before. The immediate effect of social analysis is therefore to convert the real into the rational or the contingent into the necessary. (Hirchsman 1970, 339)

Given the pandemic, planning analyses attuned to disability justice are “necessary” for this moment and any “paradigmatic” shift emergent from it.

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Utilitarianism entrenches an ethos that poses an existential threat to disability, and has led to experiences of disability being associated with deficiency, medical impairments, and social marginalization. A “rational” reading of utilitarian capacity allows utilitarian philosophers such as Peter Singer to justify the euthanasia of disabled newborns as merciful (Uniacke and McCloskey 1992). These and many of Singer’s other “rationalizations” are premised on ableist assumptions that disabled lives are less valuable than non-disabled ones, owing to individual capacity and capability, especially in relation to social reproduction.

Ableism creates the conditions for the exclusion of disabled people from equitable participation in urban life. This stigmatization and exclusion results in disability being perceived as a subpar way of existence in a normative sense. Most recently, this is represented in the rise and pervasiveness of non-invasive prenatal testing (NIPT), a method of screening in early pregnancy, which can lead to parents factoring in disability as a significant consideration when making critical decisions that can determine life or death. As biotechnology, which opens the door for ableist eugenics, continues to advance and become mainstream, how will disability and dependency continue to be perceived in society and what impact will this have on incentives for the development of critical care and support infrastructures? How are we, as planners and as inhabitants of this shared ecosystem, going to account for the threat to diversity and ranges of human corporeality and experiences that add meaning and dimensionality to human relationality? What are the complicated implications for diversity in society and environmental sustainability, if the rationale for choice and autonomy-centered right to abortion, suddenly takes on a genocidal arch? Utilitarianism, as framed by the examples above, can be an uncharitably expedient, eugenicist, and thus, a morally imperfect way to think about human worth.

Peabody-Smith (2022), countering Singer, offers a more expansive framing concerning people with profound and intellectual disabilities (PID), with relationality in mind – and upon which this thesis builds. According to her, this is a challenge of the impossibility of full communication, rather than assumptions about individual capacity and ability:

> We should wonder how much those with PID do comprehend and how much they might have to communicate. This is something many of us are familiar with doing: parents constantly wonder how much their infants understand. So do the friends of those suffering from neurodegenerative disease. Following traumatic brain injury, much effort goes into diagnosing just what patients can comprehend. This kind of wonderment is central to many of our loving or caring relationships, and it is foreclosed if the entire way we think about people with PID is grounded in a dogmatic assumption about their capacities. Why bother trying to get to know someone you see as lacking all the attributes central to personality, to an inner life, to being human? Those outside of immediate family and caretakers lack an impetus when PID is taken to be constituted solely by cognitive incapacities. However, with a degree of humility and the admission that there may be more complexity than meets the eye, our actions and interactions are positively impacted. (Peabody-Smith, 2022, 121)

If we were to adopt Peabody-Smith's framing, to guard against "foreclosures", and think about people with PIDs as "vulnerable vectors" affecting a range of dependencies, what is then the implication for disability and pandemic planning? If cities are market defined sites and loci of accumulation and agglomeration (Harvey 1985) with a propensity for utilitarianism – and urban planning is a mechanism to reign in and democratize the surpluses (Harvey 1985), then shouldn't the justification of that redistribution prioritize the most "vulnerable vectors"/non-utilitarian members of society? This lends to an argument for resourcing and designing an infrastructure of care and support that is also a counter-balancing force; one where in addition to envisioning care as an outcome, we can perhaps begin to constitute and promote an ethic of care for planning as a means and an operational value. The conceptual starting point for disability and planning then is a planning for the margins approach premised on relationality, and interdependence, and recognition of the infallible vulnerability *of all of us*, as the pandemic has abundantly made clear and as disability justice has always asserted. Especially now, at this critical temporal juncture, between the global pandemic and a looming climate crisis – where, as planners, but also as members of a global citizenry, our perspectives of ourselves, our communities, and our moral radius ought to be lastingly "upgraded."

1.2 Right to the City, Justice and Profound Intellectual Disability

"The right to the city is far more than the individual liberty to access urban resources: it is a right to change ourselves by changing the city"[15]

"The evidence of crisis and of failure to (socially) reproduce effectively…is a clear indicator of a lack of balance which requires some kind of corrective action"[16]

This thesis, in accordance with David Harvey's prescribed role for planners, aims to address a "lack of balance" in the wake of a society-wide crisis[17]—the pandemic—by seeking

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[15] (Harvey 2008, 23)
[16] (Harvey 1985, 172)
[17] He defines crisis "as a particular conjuncture in which the reproduction of capitalist society is in

answers from the field of disability justice. I argue that without considering profound disability, any iterations of the just-city[18] *oeuvre*, predicated on Lefebvre's right to the city, cannot meet its axiological aim. Disability, as the social model asserts, is not simply a biological or medical condition; it is also a social construct that is shaped by factors such as poverty, discrimination, and environmental barriers. While disability planning, in principle, can help to address these social determinants of disability by creating a more inclusive and accessible society, I want to demonstrate how it can, perhaps even more crucially, act as a common denominator across social justice issues. Further, I seek to frame disability planning as a necessary conceptual proposition for the discipline, one that invariably leads to changes in "normative" values and ethical reorientations, guided through planning instrumentally, as we prepare and adapt for various kinds of future crises.

In this section I specifically attempt to nuance and further David Harvey's articulation of Lefebvre's right to the city, with profound disabilities in mind. I demonstrate why including profound disability, specifically, as a planning conceptual priority through a guided framework is critical towards "fully realizing the right to change ourselves by changing the city" (Harvey 2008, 23), especially if Lefebvre's slogan is meant to step beyond "individual liberty to access urban resources" (Harvey 2008, 23) and inclusion through assimilation in the imparted capitalist ordering of urban space. It offers that the lenses of interdependency and vulnerability, and an emergent planning for the margins framework from it, could guide material redistribution as a

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jeopardy" (Harvey, 1985, 172). And he demarcates a role for the planner, which is to address crises borne out of imbalances caused by the propensity for overaccumulation in capitalist societies. He suggests doing so by deploying and democratizing the surpluses gathered by overaccumulation.

[18] See Fainstein (2013) and Steil and Delgado (2019) for more on theoretical articulation of just cities.

parallel process to surplus accumulation – and serve as a counter balancing and circumventing mechanism.

An articulation of this parallel process on profound disabilities, I posit, will encourage planners to contend with underlying questions of relationality, beyond simply material redistribution, in order to shape and transform urban futures premised on an endeavor for just cities. In other words, we as planners need to consider the relationships between people with profound disabilities and their communities in order to create cities that are truly just, accessible and equitable for everyone. I argue this represents a more engaged commitment for the discipline, especially (and unignorably) in the post-pandemic moment, embodying more complete ideas about transitional and transformative justice.[19]

An *Oeuvre* Informed by Disability justice

The conceptual overlaps between the social model of disability and Lefebvre's right to the city are straightforward. The social model of disability is a theoretical framework that underscores disability as a product of social and environmental barriers, rather than an individual impairment. This model emphasizes the importance of creating accessible and inclusive environments for people with disabilities, so that they can fully participate in society.[20] Lefebvre conceptualized a future in which every person living in urban areas would be afforded the chance to progress socially, economically, and politically. This vision emerged during the backdrop of the student protests that took place in France in 1968 (Purcell 2016). The right to the city encompasses not only the entitlement to utilize public spaces, housing, education, employment,

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[19] See Steil and Delgado (2019) for more on transitional and transformative justice. Haughton (2019) Calls these procedural justice and substantive justice.

[20] Modern disability rights movements and conventions such as American with Disabilities Act (ADA) and the Convention on the Rights of People with Disabilities (CRPD) are premised on these.

and other crucial amenities, but also the right to imagine how those civil liberties might be realized; by participation in shaping their materiality.

A frustration from the existing legal frames and the social contract between citizens and state motivated Lefebvre's articulation of the right to the city (Purcell 2016). Lefebvre posits that the emphasis on the individual as the singular unit of analysis is too narrow and constrains the legally enumerated rights informing social contracts. Lefebvre instead suggests that individuals exist within intricate social networks and advocated for a novel collection of rights that prioritize "social citizenship." This concept affords the ability to conceptualize with relationality (between individuals, as well as between them and their communities and the state) in mind. Lefebvre "sees the right to the city as a struggle to "de-alienate" urban space, to reintegrate it into the web of social connections" (Purcell 2016, 149). For him, achieving this right necessitates an expanded array of citizens' rights, a more substantive embodiment of democracy, and the entitlement not only to inhabit the city but also to inform the values shaping its development.

The right to the city is thus an overarching, fluid and dynamic right – an allusive right to social justice[21]. It affords a systemic recodification of values undergirding urban, spatial and relational form, as well as the lens of interdependence and intersectionality, when trying to address issues – whereas more individuated rights call for access to certain goods and services as the end of themselves. Lefebvre referred to the collaborative project of imagination towards an urban future as the "oeuvre" (Lefebvre, 1996, 66), which the right to the city envisions.

The social model of disability and Lefebvre's right to the city are both concerned with the ways in which social and environmental factors can limit people's participation in society.

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[21] David Harvey (2008), building on Lefebvre, explains how the prevailing capitalist machinery and its organization leads to an urbanization characterized by "accumulation by dispossession" (Harvey 2008, 34) – a process which creates inequity through the concentration of surpluses in fewer hands. He proposes that the route to the right to the city is by means of establishing democratic control over these surpluses as a tempering force.

However the transformational capaciousness and fluidity of the right to the city, as articulated by Lefebvre – and thus it's full potential of changing social relationality in order to change the built environment, can only be realized if there is an explicit emphasis on disability justice – especially disability justice in service of people with profound intellectual disabilities, I argue, given that the complete integration for whom requires fundamentally contending with normative ideas about self-advocacy, autonomy, productivity, mobility, care and democratic "participation." Without explicitly accounting for people with PID leads to an incomplete and arbitrary articulation of both – disability justice, as well as right to the city – as umbrella concepts, I argue.

Due to its amorphousness and open-endedness, there is potential for the right to the city to be depoliticized and co-opted for aims that can dilute its transformative potential. I demonstrate that an articulated focus on profound disabilities and vulnerable vectors as a social justice agenda helps to mitigate this, given that it cuts at the heart of underlying foundational assumptions for an array of social issues. Whereas focusing on other individual issues, often results in an overlooking of profound disability, including within disability studies.

This was apparent to me in my second semester at DUSP through the Disability and Planning speaker series at the department I helped organize. First, it was evident that the present discourse on disability and planning is Global North-centric and assumes a certain level of pre-existing services. Second, the conversation needs to be more nuanced for people with severe and profound disabilities, especially nonverbal people with disabilities, and the contingency of communicative planning needs to account for this. Lastly, moving beyond accessible design, normative ideas about care, dependency and autonomy need to be reframed through disability justice for planning.

Slogans and a Catch 22

Lefebvre's concept can be understood as both a passionate outcry and a compelling call for change, hence a “cry and demand” (Lefebvre 1996, 158) denouncing the oppressive power structures of capitalist urbanism while advocating for fresh socio-economic paradigms. He contends that by embracing *autogestión* (Huchzermeyer 2019, Purcell 2016) and engaging in social action, citizens can attain their transformative vision. Beyond its English translation as “self-determination,” *autogestión* refers to communities uniting to assume control over their surroundings and forging a new vision grounded in collective rights rather than individualism.

Similar to the sloganizing of “cry and demand,” disability justice has its own adage. The phrase "nothing about us without us" has gained prominence within disability rights movements, serving as a potent rallying cry. It encompasses a foundational principle centered on inclusivity and empowerment, highlighting the imperative of active and meaningful participation for individuals with disabilities in decision-making processes that directly impact their lives. This slogan places emphasis on the necessity of centering the voices, perspectives, and lived experiences of disabled individuals in all discussions, policies, and actions related to disability rights. By doing so, it underscores the need to discard paternalistic or exclusionary approaches that perpetuate marginalization and disempowerment. The slogan also embodies the principle of self-determination, advocating for the recognition of disabled individuals as autonomous agents with the capacity to shape their own destinies and advocate for their own rights. Consequently, adopting the mantra of "nothing about us without us" presents society with a challenge to cultivate inclusive spaces and processes that prioritize the agency, dignity, and rights of individuals with disabilities, thereby advancing the cause of social justice and equality.

While the slogans "nothing about us without us" and "cry and demand” have inherent significance in advocating for the rights of individuals with disabilities, it is important to acknowledge their assumptions and limitations in accounting for people with PID. These slogans, which emphasize the importance of inclusion, representation, and *active* participation, may inadvertently overlook the unique challenges faced by individuals with profound disabilities.

Profound disabilities refer to severe impairments that significantly impact an individual's cognitive and physical functioning, rendering them unable to fully participate in decision-making processes or articulating their needs and preferences in traditional ways. As a result, the slogans may not adequately encompass the complex care requirements, communication barriers, and diverse support needs associated with profound disabilities. Their “cry” in the cry and demand may not exist; the “nothing about us without us” can still be “without” people with PID in traditional participatory senses, if framed solely for the goal of individualized autonomy. To ensure genuine inclusivity, it is crucial to complement these slogans with nuanced approaches that specifically address the rights and well-being of individuals with profound disabilities, where perhaps we need to complement goals of autonomy and independence, with interdependence. This requires developing inclusive policies, tailored support systems, and fostering an environment that recognizes and respects the inherent dignity and worth of individuals with diverse disabilities, including those with profound disabilities. By expanding the discourse to encompass these considerations, we can strive for a more comprehensive and equitable understanding of a just built environment that is inclusive of all individuals, regardless of the extent of their disabilities.

David Harvey advocates for the consolidation of urban social movements into a unified network. According to Harvey, achieving this objective requires social movements to perceive rights as collective and actively engage with other movements. Furthermore, Harvey asserts that this movement must be *global* in nature, given planetary urbanization and globalization. In the subsequent section, I establish a connection between this global call and the inclusion of individuals with profound disabilities, presenting an ethos of planning for the margins. As demonstrated earlier, centering profound disabilities can present possibilities for thinking structurally about various social justice issues. However, failing to explicitly address this aspect may result in the exclusion of individuals with profound disabilities, as democratic processes, including those of communicative planning, are typically predicated on assumptions of participation and self-advocacy. I suggest that these movements can converge through planning for the margins, considering the varying degrees and gradations of vulnerability. By framing the intersection of profound disability within a Global South context as the lowest common denominator for questions of capacity, vulnerability and care we can foster a more inclusive, equitable, and perhaps more strategically efficient[22] approaches to collective action.

When I submitted a proposal to the department leadership at MIT, recognized as one of the foremost institutions for planning, advocating for the introduction of a disability-focused course, I received the response that the impetus for such an endeavor should originate from the students, backed by substantial numbers. This situation, considering the intricate nature of disability where its most severe manifestations render certain individuals non-verbal and with a lack of a capacity for self-advocacy, presents a catch-22 scenario. This predicament is particularly pronounced within the context of MIT, a historically and substantively ableist

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[22] Equity versus efficiency is often framed as binary in planning theory.

institution, with designed incentives and premiums for achievement and ability. Prioritizing the most marginalized and erased thus offers the most meaningful pathway towards social equity and transformation and as Umemoto (2005, 18) quoting Sandercock suggests, can be done "through learning to read symbolic, nonverbal evidence." Planners can have a crucial and critical role advocating for social equity for those who in particular cannot for themselves, such as the disabled – within or outside institutions, and this can potentially mean transformation in terms of equity in multiple domains.

1.3 Planning for the Margins

"The language and imagery of the citizen is imbued with hegemonic normalcy and as such excludes disability"[23]

"Disability can be understood as the master trope of human disqualification"[24]

This section extricates profound disability in relation to disability justice and socio-spatial justice planning theories, to highlight and make a case for its centrality in a PFM framework for the discipline. It demonstrates how firstly, disability historically has been at the bottom of social justice considerations, owing to prevailing constructions of "normalcy," and secondly, within Western disability right's movements, profound disability, and it's requisite questions for human worth defined through independence are subordinated, given the perfunctory demand on inclusion through assimilation vis a vis participatory, but individualistic, ideas of autonomy, sovereignty and self-determination, as well as the catch-22 described above.

The American with Disabilities Act (ADA) in the 90s, particular to the US, and the subsequent and more recent adoption of the UN's Convention on the Rights of People with Disabilities (CRPD) more globally, represent significant milestones in shifting from the

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[23] (Meekosha and Dowse 2001, 49)

[24] (Mitchell and Snyder 2000, 3)

biomedical approach to disability to a model that prioritizes social and human rights. However these rights based frameworks premise a model of "integration" through inclusion, rather than examining the social constitution of "inclusivity" in relation to anthropometric "normalcy." In this framing, disability remains a project of afterthought and retrofit.

Locating Disability Justice within Social Considerations

Baynton (2011) describes how disability is often subordinated or erased in social justice considerations:

> In recent decades, historians and other scholars in the humanities have studied intensely and often challenged the ostensibly rational explanations for inequalities based on identity-in particular, gender, race, and ethnicity. Disability, however, one of the most prevalent justifications for inequality, has rarely been the subject of historical inquiry. (Baynton 2011, 33)

He further notes that and that other marginalized groups are often discriminated against by attributing a lack of adequate capacity and disability to them:

> .... not only has it been considered justifiable to treat disabled people unequally, but the concept of disability has been used to justify discrimination against other groups by attributing disability to them." (Baynton 2011, 33)

Disability justice is arguably one of the most marginalized considerations even within social justice paradigms and this is reflected in the fact that other social justice issues (such as race and gender) have historically asserted their distance from disability as an expedient way to assert capacity, capability, humanity and thus inclusion. Acute and profound disability requires a contention with underlying value systems that individualize autonomy derived from assumptions of individual capacity.

Aimi Hamraie's recent work emphasizes the limits of understanding such tensions through the lens of neoliberal disability rights, which focus on individual disabled citizens/consumer “access.” Drawing on disability justice and critical access studies, they argue for a “crip mobility justice” framework that understands ableism as a structure that also works by privileging some disabled people's needs (e.g., those of wealthy, white, straight, non-profoundly disabled) over others. They emphasize that this necessarily means “a commitment to not leaving any disabled people behind” (2021) and that such an ethic “would promote cities built for the most marginalized disabled people” (2021).

While intersectional feminist design theories typically prioritize examining the interconnected dynamics of gender, race, and class, they frequently overlook or inadequately address disability as a category of analysis (Hamraie 2013). Disability is either disregarded entirely or solely approached from a medical perspective, failing to recognize its multifaceted social and material-discursive dimensions. Hamraie provides a descriptive instance of this limitation:

> In her study of diversity among architects, Kathryn Anthony focuses on a laundry list of identities—gender (construed as women), race and ethnicity, and sexual orientation (Anthony 2001, 6). Although Anthony acknowledges that the built environment excludes people with disabilities, she characterizes disability issues as outside the proper scope of feminist concerns with inequality covered in her book…because “A vast literature on universal design focusing on consumers with disabilities already exists" (Anthony 2001, 6; emphasis added) ...This "vast" literature does not, however, contend with feminist concerns with structural inequality and intersectionality. (Hamraie 2013), 13)

Centering the most vulnerable – the most voiceless and invisible – allows planners to imagine the most radically inclusive iteration of societies. It caters to the ethos of the unconditional worthiness of every person. The commitment to not leave any disabled person behind requires thinking beyond individuality and access and imagining interdependent futures. This opens up space for theorizing with dependency and creates scope for imagining radically transformational relationality – something which even decolonial mandates, which call for material redistribution, sometimes struggle to reimagine.[25] Furthermore, the nature of disability justice is such that it obligates disentangling core problems at the crux of many social justice issues, such as productivity with class politics, undervalued care-work vis-à-vis gender, normativity and queerness, and finally, incarceration and immobility in terms of abolition and racial politics. Disability as an inquiry provides immense opportunity for dismantling many systems of oppressions concurrently. Thus, it can be argued that in addition to social equity, it might also be a more “efficient” and “rational” pathway for social justice and planning overall, given how much it intersects with multiple problems.

Affordances – Planning for Disability Justice versus Rights

The concept of justice plays a pivotal role in the field of planning as it encompasses various aspects of distributive justice. Haughton and White (2019) assert that when we engage in planning, we strive to create improved environments, distribute resources, determine participation criteria, and guide governmental and private investments towards specific areas, and that these choices have redistributive implications, leading to certain places or individuals benefiting or suffering based on the outcomes.

According to Haughton and White (2019), the notion that planning is an entirely objective and technical endeavor began to fade from the 1960s onwards, as issues related to justice started permeating into the discourse. Initially, concerns about justice emerged due to public opposition to the placement of new roads, or the consequences of previous decisions that intensified polarization and socio-spatial inequalities. However, over time, these issues expanded to encompass not only the outcomes but also the processes involved in planning. People

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[25] See for example (*The Red Deal* 2021).

demanded the opportunity to have a say in the planning decisions, which exposed the technical façade of the discipline and shed light on the extent of their involvement, or lack thereof. Consequently, justice in planning is typically described as having transitional (pertaining to how we plan and what of the past comes to shape our present) and transformative (concerning the results of planning) dimensions. However, these ideas are also intertwined with critiques about the limits of participation, casting doubts on the ability of collaborative processes to achieve more equitable outcomes. Our catch-22 pertaining to profound disabilities, spelled out earlier, is one example that is illustrative of this.

Steil (2022) formulates an “anti-subordination planning,” whereby in order to achieve justice in and through planning, planners must commit to building a society where an individual's life chances are not determined by inherent characteristics. Even though he does not explicitly term disability, he nevertheless asserts that creating a society where unfair advantages or disadvantages based on ascriptive factors such as sex, gender, sexuality, race, or ethnicity are eradicated, necessitates a conscious recognition that these forms of inequality persist as systematic and asymmetrical structures of power and dominance, rather than solely individual prejudices. Rectifying these asymmetrical power structures requires an anti-subordination approach, moving beyond an anti-classification approach.

He notes that decision-making processes in planning typically fail to assess whether policies disproportionately harm certain groups based on income, race, ethnicity, sex, gender, or sexuality, and instead are concerned with fiscal impacts – and that when planning institutions evaluate the civil rights implications of decisions, they generally adopt an anti-classification approach, whereby policies should not be based on racial or other prohibited biases (Steil 2022). Consequently, rezonings, economic development policies, or other planning actions that benefit the city as a whole may be approved, even if they adversely affect historically disadvantaged groups. According to him, in order to truly achieve justice in planning, it is crucial for decision-making processes to embrace an anti-subordination approach and actively work towards dismantling these asymmetrical power structures, ensuring equitable outcomes for all (Steil 2022).

Shelton (2021) defines disability justice as “a critical, intersectional framework that names the interdependence of disability oppression with other oppressive systems/structures and advocates for the urgency of centering anti-ableist practices and values in broader movements for collective liberation.” Intersectionality is a social justice idea which asserts the principle that “nobody's free until all of us are free,”[26] and this freedom depends on creating the space and opportunity for all people to be recognized, valued, protected, and supported – without exceptions or conditions. Disability justice and the right to the the city, with their intrinsic emphasis on collectivism and intersectionality, in principle allow us to move beyond an individual autonomy centric conception of disability “rights,” and consider relationality in the mix; allowing us to “interrogate the conditions of our togetherness in the world” (Shelton 2021), as well as dependency and care. Disability justice thus ostensibly creates room for us to imagine answers through disability as a form of creative inquiry, in order to find generative possibilities, instead of treating it as an obligation, through a deficit reading.

The strategic starting point and common denominator of a justice-based system that can aspire to encompass all levels of vulnerability in any embodied sense, moving beyond tokenism, must be profound disabilities – in all their gradations and anomalies, as well as underlying

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[26] Fannie Lou Hamer, a black disabled woman, is famously known to have stated “Nobody is free until everybody's free.”

questions of dependence, care, communication, consent and self-advocacy. I further posit that in order to conceive transformative systems of care through disability justice, as well as right to the city, we need to envision with abundance instead of a utilitarian-oriented, scarcity mindset – a maximalist approach instead of a minimalist one ("unreasonable" accommodations, if you will). And profound disabilities as the starting point pushes for this. PFM articulations for profound disabilities need to not only inform both frameworks, but used to bridge the two, as a strategic dimensionality in service of socio-spatial justice through planning processes.

The Production of Normalcy and Vulnerability

The bell curve and other anthropometric and statistical ideas about "normalcy," and designing for the largest majority and averages have been pervasive within industry, but also within planning and governance ideas, and thus their study. The statistical reasoning course remains a requirement of the core curriculum across departments, including MIT DUSP. There are no parts of contemporary urban life which aren't shaped by norms, means, or averages. Davis (2018) articulates that in order to position disabled bodies as not the problem, we need to understand the construction of normalcy which is responsible for "creating the 'problem' of the disabled person" (63). He links the social processes of disabling to industrialization and the establishment of conventions of practice that shaped notions of nationality, race, gender, criminality, sexual orientation, etc., in the late eighteenth and nineteenth century. He also argues that this has led to a simplistic homogenization of disability – as a deviance from the average, thus collapsing the spectrum and scales of disability under one explanatory ambit of deviance and straying from the norm; and this is blamed for "in the long run as contributing to the disease of the nation" (Davis 2018, 70). He also notes that nearly all early statistical theorists were eugenicists and that "in any case a symbiotic relationship exists between statistical science and eugenic concerns" (Davis 2018, 67) and that they are responsible for institutionalizing the "hegemony of normalcy" (72). This standardization and condensation of ability and variation had implications for work and construction of a labor-force:

> Nevertheless, the eugenic notion that individual variations would accumulate into a composite national identity was a powerful one. This belief combined with an industrial mentality that saw workers as interchangeable and therefore sought to create a universal worker whose physical characteristics would be uniform, as would the result of their labors—a uniform product. (Davis 2018, 70)

This construction of embodied hierarchies for schematized social function and social reproduction, has parallels with the abstract spatial hierarchies imposed by modern states, as described by James C. Scott's in their well-known work *Seeing Like a State* (1998), to make their environment and human subjects ordered for the purpose of political control.

Davis (2018) further asserts that while we often associate eugenics with the racial supremacy of the Nazis, it is crucial to understand that it wasn't limited to one extremist group of right-wing fascists. Instead, it was a widespread practice among many, if not most, Europeans and Americans, and in some ways made what the Nazi's believed to be acceptable. He uses the example of Marx as well, and notes that when the concept of the average was incorporated into his formulation of average wages and abstract labor, socialists also adjacently embraced eugenic ideas. They saw the potential for improving society through the perfectibility of the human body, envisioning a utopian hope for progress. According to Davis, once the existence of norms and hierarchies in human physiology was universalized, the notion of enhancing human intelligence or reducing birth defects, for instance, no longer remained implausible.

Garland-Thomson outlined the importance of engaging with the "particularity" (2011, 593) of the differentiated forms and scales of disability, instead of imagining a theoretical, static, generic disabled body. She emphasizes how "misfit" states inform feminist conversations of vulnerability and dependence. Given the ever shifting, dynamic, spatial and temporal relationship of the disabled body with its environment, insights can emerge by "highlighting adaptability, resourcefulness, and subjugated knowledge as potential effects of misfitting" (Garland-Thomson, 2011).

Particularity, and thus the "contingency of embodiment" (Garland-Thomson 2011, 598) afforded by disability, resists the abstraction of the individual as an autonomous, independent, atomized individual, as presupposed by liberal individualism. Garland says this perspective, described titularly by legal theorist Martha Albertson Fineman (2005) in her book as *The Autonomy Myth,* challenges one of the fundamental assumptions ingrained in Western culture. I posit that an explicit articulation of profound disabilities and questions of consent and self-advocacy are useful here, because under the homogenizing umbrella of disability rights, "the myth of autonomy" is not always apparent or necessary to invoke but when planning for profound disabilities, it is necessary to grapple with.

Garland-Thomson importantly demonstrates that "the relational and contingent quality of misfitting and fitting, then, places vulnerability in the fit, not in the body" (2011, 600), and this is a seminal concept for a planning for the margins framework, as explored in the following section.

By highlighting the reciprocal nature of care and demonstrating how the dominant liberal order disregards this truth, Fineman (2005) advocates for the state to assume responsibility for care and safeguard individuals from inherent human vulnerability. According to Fineman (2005), our vulnerability, to what she terms misfitting, arises not only from our embodiment but also from the stigmatization and devaluation of care-giving relationships within the traditional liberal order.

In feminist theory, the ethics of care has long been a topic of concern. However, Fineman (2005) takes the discussion further by emphasizing the importance of legality in this discourse. Fineman argues that collective responsibility is necessary to address dependency and counteract the social injustices resulting from the subordination of dependency.

Planning for the Margins – Defining Access through Interdependence

> What price might have to be paid by people with disabilities if they engage with the increasing demands by marginalized groups to be included in what may effectively constitute token negotiations around citizenship? How do we begin to rewrite the story of what it might mean to be a disabled citizen, where the language of activity, productivity and capacity become transformed? (Meekosha and Dowse 1997, 67)

Disability activists predominantly focus on the discourse of rights and seldom explore the complex territory of responsibilities and contributions to civil society by all individuals with disabilities. This society, viewed from a disability perspective, could have a fundamentally different structure. Western political thought may struggle to adapt to the existence of citizen groups that fall outside the economic rationalist agenda – individuals who may never participate in a competitive labor market for the sake of the "national economic interest" (Shelton 2021). Women, who are often marginalized from the public sphere, face even greater marginalization when they are disabled (Shelton 2021). We need to redefine and re-negotiate an urbanism that incorporates disabled citizens, granting them an ordering of space that is cognizant of their welfare, rights and benefits while refraining from categorizing them as passive recipients.

Cities and constructed environments extend beyond their physical components; they are “material-discursive” (Garland-Thomson 2011, 592) entities that encompass both the creation of physical structures and the communication of societal expectations regarding material and social relationships. This term "material-discursive" denotes the practices that shape tangible phenomena like buildings, while simultaneously conveying messages about the possibilities for material and social connections (Hamraie 2013, 5).

The concept of planning for the margins (PFM) was developed at MIT's Center for Reflective Community Practice by Professor Ceasar McDowell with a commitment to amplifying the voices of the “voiceless.” It operates on the principle that voice equates to power and that people at the margins are living with the failures of any given system (McDowell 2015, McDowell, 2018). Parallel to the concepts of the right to the city and anti-subordination planning, PFM posits that by planning for the marginalized, we ultimately plan for everyone, including the majority. While PFM has been applied to issues like race and housing inequality, its explicit application to disability justice within urban planning has been lacking.

This omission is despite Davis’s (2018) demonstration, that disability and misfit states are marginalized or seen as deviant due to the predominance of anthropometric averages in normative civic design and policy which shape the organization of industrialized society. This is also despite Baynton's (2011) reasoning for disability justice’s subordination within social justice issues, due to underlying fundamental assumptions about individual capacity and economic productivity, and the incentive created for empowerment through assimilation for other categories, such as race and gender. This reasoning, as argued previously, can also be applied to the usually subordinate and jettisoned position of profound disability within traditional disability right’s-based movements for inclusion. Therefore, this thesis endeavors to extend the PFM framework conceptually for the first time to address the citizenship needs of this specific contingent while striving for a global, intersectional, cross-solidarity, material-discursive approach that avoids tokenism and embodies commitment.

Professor Ceasar McDowell emphasized PFM in a call to action at MIT as a compelling slogan that urged the institution to transform into an anti-racist organization (McDowell 2018). He emphasized that merely striving for diversity is insufficient due to the enduring presence of institutional and historical racism, as well as anti-blackness: “The idea here is that if you design an intervention or change to work for (and with) those who are most marginalized, then you inevitably cover them and those who are in the majority. Within the structure of the United States, it is blackness that defines the fundamental marginal group” (McDowell 2018).

Rigot (2022) offers a more global and intersectional perspective on PFM focusing on product design for tech companies, but also asserts that disability is beyond the scope of her report, which focuses on LGBTQ security and privacy vulnerabilities in international contexts. They posit that designing for the margins involves giving priority to marginalized identities right from the initial stages of ideation and creation, rather than retrofitting solutions later on. According to them, to achieve this, discussions around “consumer interests” must be reframed beyond the context of "biggest use case" scenarios and the dominant perspectives of the United States and European Union. Instead, the focus should shift to the often-overlooked cases at the margins i.e. “the decentered cases”. This approach essentially entails bringing the marginalized cases to the forefront and centering them in the planning process. They assert that “this means inclusion or diversity, as it now exists as a corporate framework, is not sufficient: our move should work towards focusing and centering the needs of those most-impacted, most at-risk and those least consulted from ideation processes to production”[27] (Rigot 2022, 2).

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[27] Rigot frames the most criminalized as the most marginalized, while framing accessibility less so in her pyramid of hierarchies. As demonstrated above, carceral practices, based on normative social priorities, conceive immobility, and thus disability, as punitive. It would have been useful if Rigot could have acknowledged this.

Rigot (2022) asserts that PFM aims to prioritize the well-being particularly of communities that are difficult to reach. It necessitates a broader perspective that goes beyond the focus on the United States and European Union, recognizing that technologies created in the West often have significant impacts on countries and contexts they were not originally intended for.

They outline that even when some level of consultation and meaningful implementation takes place, the primary focus remains centered around the United States and European Union, with later attempts to scale it to broader contexts without sufficient assessments. This perpetuates a harmful and colonial mentality within the technology sector, which is challenging to overcome. When the emphasis expands beyond the US/EU-centric perspective, it often becomes driven by capitalistic profit-seeking and competition in "emerging markets." However, marginalized individuals outside of these US/EU frameworks, bear the greatest burden of inadequate design practices (Rigot 2022). In these circumstances, where the development and design processes embody Western-centric perspectives, technology, in her examples, further harms vulnerable and hard-to-reach populations (Rigot 2022).

While limited in their conception by assigning “consumer power” to the most marginalized, Rigot’s international assertion for a PFM framework is important, because it creates space to tie in David Harvey’s assertion (2008), that due to neoliberalism and global financialization, the urban scale has transformed into a global scale, and that any collective movement building around the right to the city, “at this point in history, has to be a global struggle” (Harvey 2008, 39).

Neoliberal financial hegemony injects and imports values of transactionality, individualism and competition, giving rise to the image of cities “as inhuman or transhuman entities" (Thrift 2004, 57). This has consequences for erosion of valuable pre-existing trust and kinship support networks in traditional localities characterized by collective values, rather than individual ones – and where this form of "capital" is especially valuable, given material and resource scarcity. This can translate into even more dire consequences in terms of survival of people with major care needs and dependencies, including those with profound disabilities – and yet this is not recognized, imagined or preemptively addressed by planning agendas operating under neoliberalism, due to the catch-22 described above and assumptions about normative individual capacity, self-sufficiency and self-advocacy.

Harvey importantly highlights that neoliberalism has given rise to models of governance around the world that blend state and corporate interests and that "this is a world in which the neoliberal ethic of intense possessive individualism, and its cognate of political withdrawal from collective forms of action, becomes the template for human socialization" (2008, 32). He describes "creative destruction" (Harvey 2008, 33) as a troubling process that leads to the absorption of surplus resources through frequent cycles of urban restructuring. This process tends to disproportionately affect the poor, underprivileged, and politically marginalized individuals, as they are the ones who bear the brunt of its consequences. He notes that "violence is required to build the new urban world on the wreckage of the old" (Harvey 2008, 33).

He argues for the unification of call for social justice, globally, under one right to the city banner to regain democratic control of the surpluses to create equity and a just urban form, "as both, working slogan and political ideal, precisely because it focuses on the question of who commands the necessary connection between urbanization and surplus production and use" (Harvey 2008, 40). To achieve this goal, Harvey argues that not only must social movements in cities see the right as collective, they must also make conscious efforts to reach out to other movements. For Harvey, as moted, this movement is necessarily a global one.

In this thesis, I offer that a PFM framework can be aligned with Harvey's assertions; and that by also necessarily incorporating an intersectional perspective, it will have to address vulnerability resulting from non-normative "misfit" states across various identities and regions, considering their different vectors, gradations and scales. An intersectional lens is crucial for any embodied commitment to a PFM framework that seeks to redirect surpluses toward the envisioning of more just and inclusive cities, not only in material terms but also in relational aspects. Profound disabilities, as a socio-spatial category, and the questions of voicelessness and limited self-advocacy, require analyzing urban planning through the additional lens of dependency beyond individualized autonomy. Prioritizing this contingent is essential for any PFM framework that wishes to pull its weight and claims; where a relational ethic of kinship and care can be preserved – and perhaps even be intentionally globally constituted at a moment when neoliberal financialization and mass consumer supply chains primarily dictate the terms of interconnectivity and cooperation between global urban centers.

Both McDowell (Bogen 2016), and Rigot (2022) neglect disability in their canvassing of PFM, yet offer the example of the curb-cut as an example of planning for the margins, highlighting how a design intervention in public space for disabled WWII veterans who used wheel-chairs, ended up benefiting the wider public such as parents using strollers, cyclists, cart-vendors etc.

This example needs to be ferociously nuanced in terms of PFM in relation to disability justice. Rather than an example of PFM, the curb cut is more representative of universal design (UD), and we need to be cognizant of the overlaps, as well as salient differences in principles guiding both, in order for PFM to intentionally fulfill the agenda outlined in its name. It is a useful example in terms of defining “access” for a disability-justice informed PFM, in relation to UD – and outlining what it means to perhaps design for particularity, rather than generalizability; to adopt a maximalist approach premised on conceptualizing abundance, instead of a minimalist one predicated on scarcity.

UD emerged from a desire to enhance the accessibility of aesthetics and functionality, shifting away from perceiving disabilities as an added, exceptional, and unconventional factor—essentially moving beyond the concept of a "special need" (Hamraie 2013). The objective was to make access more widespread and reduce the emphasis on disabilities as something separate or supplementary (Hamraie 2013).

Hamraie (2013), in their critique of consumer-oriented approaches to UD from a social justice approach to accessibility, notes broad accessibility (accessibility for the greatest number of people possible) and added value (design that benefits disabled people which also has benefits for nondisabled people) as two main ideas underpinning UD. Both of these can be framed as akin to the “biggest use cases," the very concept which Rigot tries to counter by highlighting curb-cuts as a misguided example for PFM.

When designers assert statements like "it's impossible to accommodate everyone; there have to be boundaries," they are essentially creating misfit. These acts of drawing lines or setting limits are practical and communicative actions that influence which bodies are considered possible and likely to exist in the world. However, design is a subjective endeavor based on values, and not all human variations can be easily encompassed within a one-size-fits-all framework (Hamraie 2013). In the absence of specific guidelines, UD can easily adopt vague notions of inclusivity, assuming normative users and disregarding the needs of individuals with profound disabilities. For instance, curb cuts have proven beneficial for a wide range of people, including wheelchair users, stroller users, and cyclists. While this claim implies that these design features serve multiple purposes, not all of these uses were intentionally considered during the design process (Hamraie 2013). The values and knowledge systems that determine how wheelchair users, cyclists, and people pushing strollers are included in the concept of "all" and "everyone" are not thoroughly examined. Broad accessibility means the widest number of categories the design can cater to, not necessarily the most marginalized, or those that may slip out of this wide net, still, for example the profoundly disabled – for whom indeed curb cuts and material design access may be important, but equally are conversations on care, dependency, and who might be there to push their wheelchairs across these curb cuts. I propose that the concept of PFM, with its unwavering focus on those at the absolute margins, allows us to move beyond seeing accessibility informed by UD as the bare minimum common denominator. Instead, PFM urges us to aim ambitiously for a maximalist approach that seeks to include everybody, embracing their unique physical and personal needs through care and interdependence. This approach rejects a scarcity-minded design perspective that aims for generalizability but may fail to meet the diverse requirements of individuals.

The emphasis on added-value positioning of UD, and PFM by Rigot, might lead to the perception of these approaches as being primarily concerned with individual consumer products and assistive technologies tailored exclusively for people with disabilities. This perspective can narrow down the understanding of disability and accessibility to a purely individualized issue that requires consumer-based solutions. Consequently, PFM, as suggested by Rigot, might then be flattened, depoliticized and limited to niche consumerism, rather than being recognized as a comprehensive and intersectional social justice method; an approach that offers designers a way to address broader and interconnected issues of exclusion from the built environment that affect diverse groups collectively, with overlapping and intersecting challenges.

The concept of added value becomes a part of UD when it aligns with industrial and product design, which have a history of focusing on efficient mass production for consumers. Added value refers to designs that are consumed individually or boost profits for manufacturers (Hamraie 2013). As a result, the notion of added value does not prioritize the elements of accessibility that foster cooperation and interdependence among different individuals. Even though examples of UD with added value may not be seen as explicitly related to disability, they still promote a fragmented approach to achieving social justice objectives. This approach relies on individual access to consumerism rather than addressing broader issues of inclusivity and interdependence (Hamraie 2013).

In this era of late capitalism, industrial design and product design have embraced the principles of neoliberalism, which involve the large-scale production of individual products and technologies that are adaptable and accessible to the standardized majority. This approach allows designers, manufacturers, and builders to reap the economic advantages of economies of scale by creating single designs that can be sold to a wide range of potential consumers. This system is predicated on the idea of the atomized, self-sufficient, earning, economically productive consumer. An emphasis on profound disabilities through PFM, I argue, cannot miss the particular and “bespoke”[28] nature of dependencies, mandating a reckoning for putting in place a care infrastructure that is necessarily relational, abundant, flexible. customized and cannot be mass produced through scale economies; an antidote and parallel process to neoliberalism and erosion of kinship, globally.

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[28] Borrowing another term from Sara Hendren.

Considering that design is a material-discursive and a value-laden practice (Hamraie 2013), a PFM approach, informed by disability justice, needs to ascertain what all may planning for interdependence entail, informed by treating misfit interactions between bodies and their environments as an inquiry. All bodies need care and kinship, and thus interdependence. The subordination of dependence leads to shame around acknowledging and admitting this. An understanding of access as interdependence is needed, and a useful one is provided by Shelton:

> Access has a special place in disability studies as well as the disability justice framework and movement. Disability justice activists like Mia Mingus (2017, 2018) and Leah Lakshmi Piepzna-Samarasinha (2018) consider access to be more than a simple, standard, or politically neutral thing. For these activists, the notion of access refers to a process of interrogating the conditions of our togetherness as a means of resisting ableism – the social, cultural, and political system which devalues disabled people, our bodies, and our minds. Additionally, access revolves around the recognition of our needs as interdependent, living beings and the making of communities of care wherein people commit to supporting and moving with each other (Sins Invalid 2016). In line with these critical theorists and activists, I argue throughout this paper that access is not a matter of individual bodies or even disability in particular; to the contrary, access emerges in the contexts of liberating and sustaining relationships between people (Berne et al. 2018), and it disappears or shrivels up when relationships and sense of belonging become predicated on the denial of our embodied needs such that we do not obtain the care we need. Moreover, from a disability justice perspective, access is not singularly about disability but instead must be defined and approached intersectionally, that is, with critical attention to the ways in which different identities, social locations, and systems of power interlock with and shape each other (Crenshaw 1991; Knoll 2009). (Shelton 2021)

PFM based on disability justice, collective access, and interdependence can understand value-explicit design as a form of activism within design professions. Urban planning practitioners and theorists, building upon the theory outlined here, could continue to develop strategies for participatory design, shifting from value-explicit design for disability to design with and by misfitting bodies more generally. These subtle but salient differences in framing could shift both the role and work of designers, as well as render PFM as a more capacious and social justice-oriented material-discursive practice, where care is procedural but also an antisubordination outcome, embodying the adjacent converseness to overaccumulation, as a counterbalancing pathway.

Thus, a reading of care through profound disabilities is essential for a PFM framework, and centering particularities of embodiment is where the common denominator needs to be implanted, especially if the theory is that "designing from the margins benefits all, and that what is created for the decentered cases will always be generalizable for the broader usership" (Rigot 2021, 2). Aspiring for care as a social justice outcome, entails building worlds in which we can co-exist with one another in interdependence because we have collectively built the conditions necessary for everyone to be present and in the right relationship (Shelton 2021).

In this section I tied the global rights to the city call and antisubordination planning with profound disabilities to articulate a planning for the margins ethos. As demonstrated above, without an articulated focus on profound disabilities creates a propensity that can exclude this faction, given how democratic processes are designed on assumptions of ability to "participate" and "self-advocate." In the ensuing sections, I articulate how these movements can come together through a planning for the margins ethos with gradation of vulnerability and misfit in mind, framing the intersection of profound disability in a Global South context as the lowest common denominator. This follows a discussion on the need for a missing urban infrastructure of care, as a preemptive counter balancing mechanism and an opposing but adjacent process to global financialization, and the precarity it engenders.

Chapter 2: Conceptualizing Care

2.1 Disability, Abundance and "Normativity" of Care

> *"It's that the stakes for life together are universally shared by the misfit states that come for everybody. We find ourselves in need of assistance—some of it from the forms of the designed world and some from one another, body to world and back…human needfulness really is universal."*[29]

This subsection aims to assess and anchor conceptual framings of care work, autonomy, and dependency by applying a critical disability studies lens to contemporary feminist discourses on these topics. It critically examines certain aspects of feminist literature that label the idea of "self-care" and choice, premised on individuality, and accompanying ideas of self-sufficiency and independence, as "anormative care." It seeks to illuminate and challenge the ableist assumptions perpetuated by these discourses, which marginalize conceptions of needfulness and dependency, while completely disregarding disability and its inherent entanglement with dependency. This section questions the underlying assumptions of scarcity that underpin the scarcity of care, advocating for a more imaginative approach to envisioning futures that acknowledge and celebrate interdependence and dependence, and the ensuing need for imagining infrastructures of care from a place of abundance. This perspective does not undermine the pursuit of independence and autonomy through self-care but rather calls for their integration within a broader framework of care.

Care has been a foundational concept within feminist scholarship, serving as a crucial framework for understanding the intersections of intimacy and labor. Earlier feminist literature primarily addressed the challenges associated with undervaluing women's domestic care work. However, contemporary scholars engage in debates surrounding the purpose and scope of care,

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[29] (Hendren 2020)

including discussions on whether care can be effectively provided by individuals who are physically distant, how power dynamics in caregiving should be navigated, and the intricate relationship between care and values such as justice, trust, and autonomy (Cooper 2007).

The presence of profound disability, characterized by an inherent need for assistance, requires a dissolution of individualized boundaries between caregivers and receivers, impacting traditionally imagined dynamics and limits of human empathy and dependency. Conceptually, it necessitates an intentional framework that is conceived on interdependence, instead of independence and, I argue, that this serves the basis of “anormative care.” However, recent feminist scholarship appropriates the term "anormative care," a constituent term from disability studies, to denote self-care practices motivated by autonomy and independence. However, this application proves inadequate and counterintuitive, as it fails to encompass the wide, but creative, spectrum and magnitude of needs and needfulness that disability, especially profound disability, entails. By neglecting to account for the diverse manifestations of interdependence and dependence, alongside the pursuit of autonomy and independence, this characterization undermines a comprehensive understanding of disability and its multifaceted nature and the imaginative possibilities it can inspire.

In order to fully grasp the importance of thinking and conceiving care through abundance, it is useful to compare it with the implications of care, which we can see today around us, derived from the prevailing scarcity mindset. Fujikane (2021) argues that neoliberal capitalism is intrinsically marked by the fear of abundance, because a just redistribution of resources poses an existential threat to it. The recognition of abundance challenges an economic system that thrives on unmet desires. While Fujikane specifically focuses on the interdependence of land and people, her critique of deficit-thinking and the need for an abundant-minded approach applies to disability as well. Historically, disability has been approached through scarcity and deficit-oriented perspectives, perpetuating the belief that disabled individuals need to be "fixed" or passively receive assistance, known as the "charity model" of disability. This model objectifies people with disabilities, impeding justice and contributes to ableism.

Cooper (2007) categorizes the interlock between needfulness and care as "normative care." Her examination of care ethics in a women's bathhouse, when juxtaposed by ideas of dependency in relation to disability, helps clarify the normative or anormative nature of care, and this diverges from her conclusions. Cooper portrays care as an asymmetrical orientation toward others, often idealized and sanitized (2007). Cooper argues that "anormative" care, as practiced in the women's bathhouse, is not dependent on need, but rather centers around caring for autonomy and self-fulfillment.

Cooper subordinates the normative feminist model of care, merging it with religious agape to promote an ethos of “independent autonomy” (2007). This perspective defines anormative care as self-care and consumption. However, her model and direction of "anormative" care is susceptible to cooptation by neoliberal ideas of individual self-sufficiency, and thus cannot sufficiently depart from normative and predominant ideas about conventional liberal autonomy. I argue that Cooper fails to address anormative care practices in relation to disability and extend the scope of her analysis beyond a scarcity-minded approach. She argues that tying care to need reifies a hierarchy between caregiver and recipient, and thus, normalizes potential harms that may befall the recipient, if in case they are not cared for, and that this framing of care is responsible for normalizing vulnerability and precarity. This is at odds with the understanding, demonstrated heavily in the previous chapter, that it is the states of misfit created through prevailing ideas about the “self-sufficient individual” *within* neoliberalism – and its accompanying incentive structure which undermines and undervalues care, and engenders a scarcity of care-giving, which creates precarity; not care for the other by its standalone self. Additionally, she suggests that normative care, as framed by her, is not a systemic solution to the problem of need and scarcity of care, which I counter here by articulating that conceptualizing a social structure with an *abundance* of care flushes out hierarchical models based on need. And that it makes more inclusive sense to frame anormative care as care that is necessarily particular and "bespoke," derived from a place of centering interdependence, progressing from ideas of individual independence, and that which holds on to aims of social citizenship and defines autonomy as a collective autonomy – and which encompasses and imagines the diversity and dynamism of all ranges of embodiments and misfit states within its moral folds. And that which does so without erasing the labor involved or by undervaluing it as a gendered practice.

Piepmeier (2013) provides a useful example which demonstrates the importance of a maximalist and abundant approach to care, and how an individualized "choice" based feminist and reproductive rights-based approach to NIPT and disability can fall short. In her research she talked to parents and potential parents facing such a choice, and I reproduce two illuminating examples:

> By articulating that the decision was all hers, one that they would support, Leanne felt that her parents were giving her the message that she should terminate, thus adding to her feeling of isolation. At this moment she was eager for a different kind of support, a family community that would help her navigate having a child with a disability. By articulating that the decision was all hers, one that they would support, Leanne felt that her parents were giving her the message that she should terminate, thus adding to her feeling of isolation. At this moment she was eager for a different kind of support, a family community that would help her navigate having a child with a disability. An emphasis on individual choice is pervasive in much feminist writing about reproductive rights, but these interviews demonstrate that individual rights and responsibilities don't solve all problems or even explain them. These women didn't discuss the individualized decision-making process as empowering, with meaningful options available to them. Instead, they felt frightened and pressured, as if those around them had unpredictable

> agendas that had to be negotiated and manipulated. These stories illustrate the complexities that can characterize reproductive experiences, complexities that need to appear in feminist discussions of reproduction. (Piepmeier 2013, 175)
>
> In our conversation, Diane revealed the complexity of this sort of thought process. There were no easy narrative frameworks for explaining her experience. A feminist assertion of Diane's right to make a "choice" doesn't help her figure out what "choice" means in her individual context. She knew that she had a "choice," but she wanted something more: guidance, information, real options, meaningful support. One helpful circumstance was her relationship with her boyfriend's father and stepmother, who was pregnant at the same time. Their support and sympathy for her challenging situation—their offer of food as well as their offer of in-utero comparisons — made the process easier for her. (Piepmeier 2013, 173)

The instances mentioned by Piepmeier shed light on the complicated contours of isolation versus empowerment experienced by pregnant women, as they navigate the complexity of individualized choice regarding pregnancy termination and disability. These interviews ultimately revealed the limitations of framing their experiences solely within the narrative of feminist "choice" and lapsing individualized choice with self-care, by itself, as argued by Cooper (2007). They also point towards the importance and urgency of developing infrastructures of care and support from a place of abundance.

2.2 A Missing Urban Infrastructure of Care

> What would it mean for planners to care about care? As both means and ends to social, economic and spatial justice care should concern planners, who should strive to ensure the reproduction of care work through their practice. Care holds potential for the planning field as a framework for attention that would allow practitioners to better understand the types of social relationships that produce resilience at the community-scale. Care can also be seen as a framework for action, for an ethical practice that attends to and supports ordinary acts of resilience, reworking and even resistance on the city's margins with a view to establishing and maintaining the conditions for a pluralistic and democratic urban life rather than trying to solve social challenges as if they were technological problems. (Binet 2015)

This section delves into a spatial conceptualization of care within the realm of urban planning. It heavily draws on Binet et al.'s (2022) framework which anatomizes a missing urban infrastructure of care. Though Binet et al.'s framework was developed without explicit consideration of disability planning and conceptualized children as dependents, it is a critical bridge between spatial justice and questions of care for planning. They focus on children because childcare is a common and recognizable form of care in cities, especially in terms of facilitating social reproduction.

Binet et al. (2022) frame the crisis of care as an inherent aspect of capitalism and its manifestation in urban settings, and they argue that central to this is an analysis of whose mobility is rewarded by our infrastructure, who gets to receive protection from municipal systems, and who is granted access to public spaces. They argue that while care has not played a significant role in planning, the way cities are planned and designed profoundly impacts the ease or difficulty of accessing care. Two concepts are employed: "landscapes of care" from geography, which examines the spatialization of care and its influence on experiences, encompassing scales such as families, institutions, and global migration chains; and the anthropological concept of "stratified reproduction," which highlights how certain power groups are empowered to nurture and reproduce, while others are disempowered based on factors like class and race, thus shaping access to care-related resources. The concept of "care binds" is introduced, underscoring the significant consequences faced by caregivers and dependents when necessary infrastructural support is lacking in the urban environment. The term "infrastructural labor" is used to describe the burden that caregivers must bear due to inadequate infrastructure, which varies depending on the contextual conditions. The uneven and unequal distribution of this infrastructural labor, along with its inherent precarity, contributes to the stratification of reproduction and exacerbates the crisis of care within urban development patterns.

Binet et al. (2022) argue that care is not a separate, isolated concept, but rather intricately tied to the functioning of cities and the livability of urban spaces. Scholars have argued that care itself constitutes a form of planning, yet the process of neoliberal urbanization driven by capitalism has marginalized and devalued care. They argue that planning tools possess the potential to address the crisis of care meaningfully, and it is asserted that planning for health necessitates incorporating planning for care as an accompanying component. In this context, planning for care involves prioritizing care as a desired outcome, similar to the way people require mobility within a city. Thus, it is crucial to make care visible and recognize its value. Guided by this perspective, planning for care should focus on two objectives: firstly, alleviating and equitably distributing the burden of care work by expanding caregivers' freedoms to give and receive care in ways they value, and secondly, fostering a diversity of possible forms that care can take.

Lastly, Binet et al.'s (2022) model treats care as both work and a value, and they assert that it is essential to maintain this dual perspective. Planning should not only account for care but also be imbued with care itself. Planning for care, as an ethic, connects to the subsequent discussion on communicative planning and inclusion for individuals with profound disabilities.

Communicative planning is a planning approach that prioritizes open dialogue and active engagement among diverse stakeholders to create equitable and informed decision-making through self-advocacy, inclusion and collaboration. Self-advocacy, in the conventional sense, is foreclosed when we think about people with profound disabilities and communication barriers. Binet’s assertion of care as an ethic for planning processes, makes it possible to conceive a more inclusive and expansive baseline in terms of thinking through communicative planning processes within PFM for this particular subgroup.

Chapter 3: A Disabled Environment Meets a Disabled Body

In this section I describe and discuss my observations and field-work visits to Slovo Park, an informal settlement located on the outskirts of Johannesburg, South Africa. Previously, I suggested a PFM framework that is 1) cognizant of disability, especially profound-disability and the care precarity engendered by urbanization and financialization through neoliberalism – and 2) which envisions designing a care-infrastructure as a premptive, parallel but oppositional, antidotal process to global neoliberal accumulation. This next section moves towards the environmental context of my research.

Throughout my time in planning school, I was captivated by the degree to which descriptors used by planning theorists to characterize urban informality, a phenomenon largely thought to be a feature of the Global South, demonstrated a notable interchangeability when applied to the domain of disability — particularly through a rendering and reading of both that is thought to be "unplannable" (Roy 2005). Urban informality refers to the unplanned and often marginalized aspects of urban environments, encompassing informal settlements, informal economies, resource-scarcity and inadequate or absent infrastructure.

Before venturing into a more parsed discussion of the overlaps between disability and urban informality, it is first useful to do some table-setting on the conceptual tensions raised by scholars, when theorizing disability in the Global South. In the next sections I summarize some of these, followed by conceptual overlaps in planning specifically between urban informality and disability. These are followed by my findings from Slovo Park and a discussion of the preliminary conclusions that become incandescent when misfit bodies intersect with misfit environments.

3.1 Global South and Disability

Figure 1: A picture I took of my feet at the Apartheid Museum's display reconstruction of one of twenty-six isolation cells in the former Number 4 Prison at Constitution Hill, established to house black male prisoners during the Apartheid era.

As definitions of civil rights and citizenship have expanded, there is a simultaneous erosion of access to essential resources for livelihoods in Global South contexts. This disconnection between civic and socioeconomic realms is evident in the case of countries like post-apartheid South Africa, where socioeconomic inequalities have escalated despite the expansion of political and civil rights for citizens (Miraftab 2009). In the current neoliberal era, universal formal citizenship has resulted in selective material inclusion. While individuals may experience increased *de jure* access to state institutions and opportunities for civic participation, as well as social and political inclusion within the state, this does not guarantee *de facto* inclusion. Literature on disability and citizenship in the Global South articulates the possibility that, by solely concentrating on human rights, the problems faced by disabled people may be further exacerbated rather than solved (Meekosha and Soldactic 2011).

Meekosha and Soldatic (2011) highlight that individual rights are not universally understood, but instead reflect the dynamics of industrialized societies, which may differ from more traditional community structures found in agricultural-based countries in the Global South. Human rights originated from Western liberal traditions, whereas non-metropole cultures have distinct traditions of emancipatory and collective struggle (Meekosha and Soldactic 2011). This finding mirrors our conclusions in Section 2, pertaining to an explicit focus on profound-disabilities, and questions for relationality and limits of rights solely premised on individualized ideas of autonomy that arise.

In the Global South, impairment or harm is often a result of the legacy of invasion, colonization, and globalization, leaving many disabled people living in poverty. In his talk at DUSP on April 15th, 2022, Professor Michael Stein asserted that without explicitly considering disability, poverty alleviation efforts perpetuate inequity. According to Grech and Sodactic (2016) the discourse between disability and the Global South often relies on oversimplified and generalizing statements, such as the concept of a poverty and disability cycle. According to Grech, this notion tends to overshadow a deeper and more critical understanding of poverty, and in this schematic, “poverty and disability appear to never actually meet” (Grech and Soldatic 2016, xx).

Considering the close connection between poverty and disability, Meekosha and Soldactic (2011) suggest that redistributing power and wealth, both between rich and poor countries and within poor countries, could have a greater impact on the lived experiences of disabled individuals in the Global South compared to relying solely on human rights legislation. Human rights instruments do not address wealth and power distribution, which historically has required struggles by the powerless.

Furthermore, this legacy of domination, most recently reified through neoliberal urbanization and financialization, represents a “politics of impairment,” and impairment cannot be separated or detached from the lived experiences of disabled individuals within their social reality (Meekosha and Soldactic 2011). Drawing on Connell's “ontoformative” concept, they emphasize that while disability is recognized as a result of bodies in social dynamics, it is important to acknowledge the influence of global power dynamics on bodies, which become embodied as a social reality – a perspective often absent from Northern framings of disability rights (Meekosha and Soldactic 2011).

Puar (2017, xv) employs the term “debility” to refer to the temporal and spatial framework that is overshadowed by the exclusive focus on “exceptionalizing” disability and exceptional disability, highlighting debility’s endemic nature. She notes:

> The biopolitics of debilitation is not intended to advocate a facile democratization of disability, as if to rehash the familiar cant that tells us we will all be disabled if we live long enough. In fact, depending on where we live, what resources we have, what traumas we have endured, what color our skin is, what access we have to clean water, air, and decent food, what type of health care we have, what kind of work we do…we will not all be disabled. Some of us will simply not live long enough, embedded in a distribution of risk already factored into the calculus of debilitation. Death’s position. Others, at risk because of seeming risky, may encounter disability in ways that compound the debilitating effects of biopolitics. (Puar 2017, xiv)

She further argues that state discourses of inclusion utilize the concept of disability, not only to conceal various forms of debility, but also to actively generate and perpetuate debilitation. While one definition positions disability as a “privileged category” due to state recognition, another definition sees disability as the embodiment or subject that, despite experiencing unexceptional and endemic debility, can still strive for economic and emotional well-being, empowerment, and pride through its “exceptionalized” status (Puar 2017). Caretakers of individuals with disabilities often come from marginalized populations that themselves experience chronic debilities. The recognition of disability by the state, medical institutions, and other authorities may obscure debilities and processes of gradual decline which she terms “slow death” (Puar 2017, 2), while also allowing it to disregard the everyday manifestations of widespread debilitation caused by capitalist exploitation and imperialist expansion. She notes that the assemblage of disability as an ascriptive category, especially in the Global North, is influenced by heterogeneous forms of capitalism, care, and racialization, encompassing a constellation of debilities and afforded and negotiated capacities. In reference to other current movements, she notes:

> At our current political conjuncture, Black Lives Matter, the Palestinian solidarity movement, the protest against the Dakota Access Pipeline to protect sacred grounds and access to water: these are some of the movements that are leading the way to demand livable lives for all. These movements may not represent the most appealing or desired versions of disability pride. But they are movements anchored, in fact, in the lived experiences of debilitation, implicitly contesting the right to maim, and imagining multiple futures where bodily capacities and debilities are embraced rather than weaponized. (Puar 2017, xxiv)

The politics of impairment complicates the understanding and recent positioning of disability, predicated on the social model of disability, that asserts that disability is not diminishing per se and which moves the location of the disability out of the person and into social structures.[30] This points to a need to develop “accounts of embodied aspects of disability such as pain and functional limitation without giving up the claim to disability as a social phenomenon” (Garland-Thomson 2011, 592).

The emergence of an overarching disability rights discourse, rooted in Northern concepts of disability, contrasts with Connell's ontoformative concept. Meekosha and Soldactic (2011) note that the disability rights movement, predominantly led by Northern actors, has aimed to

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[30] I started wondering if a desire-based framework (Tuck 2009) of the social model of disability allows for more violence?

engage with the politics of disability by separating impairment from disability and addressing structural, social, and attitudinal barriers to inclusion. The ontoformative concept provides an avenue to bridge the politics of impairment with the politics of disability, allowing for a deeper understanding of disabled experiences and the recognition of the broader politics of impairment within the disability rights movement. For planning, this concept also helps to inform how we understand the "environment" as conditioned by local and global structural forces and priorities, which create debilitation, "slow death" and impairment.

Informality and Disability

"To deal with informality therefore partly means confronting how the apparatus of planning produces the unplanned and unplannable."[31]

An estimated 32 percent of the world's urban population lives in informal settlements (Sandoval and Sarmiento 2020). Of the 10 percent of the world population that is estimated to be disabled, four-fifths reside in the Global South (Capri et al. 2018). However, the conceptual overlaps in the socio-spatial production of disability and urban informality have not been articulated yet. Informality is a "continuity and a contradiction" (Huchzermeyer 2019, 469) of legal formalization, just as disability is a co-construction of ability. Both are material-discursive phenomena, and both have histories of being framed as "unplannable," disorderly, transgressive and as aesthetic aberrations. Both are conversely tied to ideal and normative ideas about "functionality," and both are differentiated processes embodying varying degrees of power and exclusion. Sara Hendren asks us to pay attention to the "wonder of adaptation" when thinking about disability, and Richard Dobson, in his interview with me for my research, also described informality as "nimble and adaptive." Both are sometimes also (incorrectly) thought to be

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[31] (Roy 2005, 156)

isolated from global capitalism. Both require us to think temporally about economic growth. And finally, both raise intriguing questions about bodily and territorial sovereignty, respectively, which the findings of this thesis later point to.

What can we learn from the domain of disability studies, towards thinking about urban informality – and vice versa? We have devoted ample space to discussions of disability in earlier sections, therefore the rest of this section gathers perceptions and approaches to informality, tying them in with disability as needed.

Municipal administrations often perceive informality as an inferior and illegal type of urban mode of service provision for the urban poor. To enhance its conditions, they typically focus on physical improvements and call for its integration into formal planning processes. Yet, these policies have often failed to improve the well-being of those involved in the informal urban sector. Examining these policies reveals generalizations and assumptions about informality (Roy 2005).

Development initiatives in the Global South mainly aim to upgrade the physical standards of informal housing settlements through better infrastructure and facilities. However, by solely linking physical upgradation to an improved quality of life, these policies overlook the basic needs of informal settlements, sometimes exacerbating hardships instead of addressing them. This approach can be likened to the medical model of disability, which seeks to fix or cure disability, perpetuating a diminished perception of disabled corporeality. Furthermore, these policies neglect the larger issue of excluding informal settlements from the broader urban fabric, including transportation systems and social networks – incidentally and conversely reflecting the social model of disability's emphasis on the social determinants of disability.

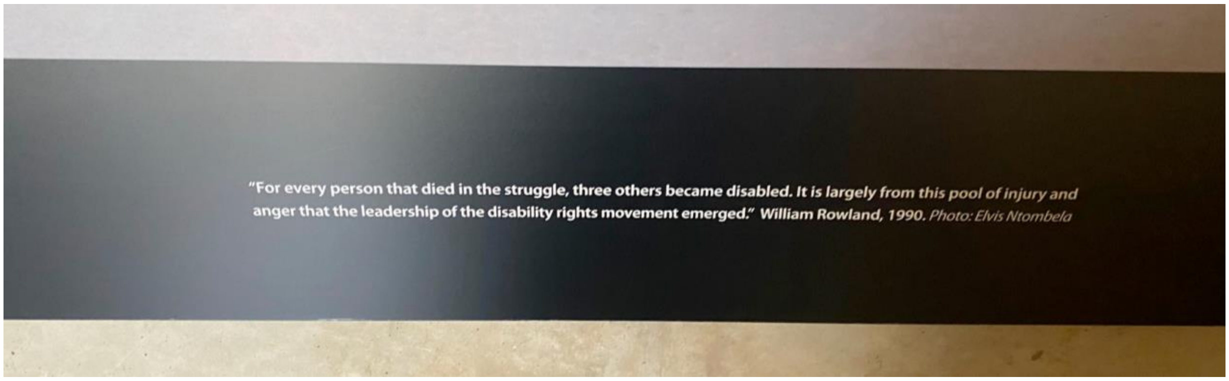
Another policy approach is to eradicate or relocate informality to the outskirts of cities, similar to the institutionalization of disability and its removal from urban visibility. Urban administrators often favor this approach, perceiving informality as disruptive to urban order. These policies often rely on stereotypes of portraying informality as chaotic, dirty, or associated with criminal elements, even if these perceptions do not reflect reality. Informality may seem disorderly if its production in relation to economic growth is not understood, but it does possess its own dynamics, internal organization, and differentiated patterns of existence (Huchzermeyer 2019, Roy 2005).

Efforts to formalize informality, such as providing vendor permits, titling informal settlements, and implementing specific zoning laws, face similar shortcomings, since these policies can overlook the hierarchy embedded in the state's interaction with informality, when approaching it from the lens of “fixing” it. While these measures may seem progressive, they perpetuate a binary that presents formalization as the only viable option while not being attuned to underlying power structures. Scholars have highlighted severe ethno-racial discrimination in the state's approach to informality. Forcing informal systems into legal frameworks does not necessarily enhance their economic functions because it is not considerate of the vulnerabilities faced by those dependent on informal systems, including discrimination, limited access to capital, strained relationships with law enforcement authorities, and exclusion from formal and informal social and kinship networks that provide protection and support. Again, *de jure* access and inclusion does not sufficiently translate to *de facto* access and inclusion. Recognizing the diversity and internal dynamics of informality, there is a growing acknowledgment that planning agendas should be tailored to the needs of informality's participants – and, yet again, a PFM framing may be useful here. Similarly, as argued for disability above, conceptual framings of informality should consider both its particularistic and general aspects, treating it as a generative inquiry – mapping the networks, interactions, and movements within informality while considering its dynamic nature.

Given some of the conceptual overlaps, what does then the intersectionality of profound disability and informality mean, in terms of a misfit reading of compounded vulnerability and PFM? What does informality spatially mean for profound disability? And the converse? What do care networks for profound disability look like in an informal setting? Have they transformed or eroded overtime? Are there ways in which informality is beneficial for profound disability? And vice-versa? Can there be reparative policy recommendations for erosion of care networks in resource-scarce communities due to urbanization stemming from top-down, market-driven, global neoliberal, incentive structures? Given the role of race in South Africa, what are implications for profound disability in a post-conflict context? And has distance from disability been used as a way to assert economic capacity and thus inclusion?

These were some of the general preliminary questions guiding my research for this thesis.

3.2 Johannesburg and South Africa



"For every person that died in the struggle, three others became disabled. ***It is largely from this pool of injury and anger that the leadership of the disability rights movement emerged."*** **William Rowland, 1990.** *Photo: Elvis Ntombela*

Figure 2: My photo of a caption under a picture at the Apartheid Museum of a marathon organized by the Self-Help Association of Paraplegics in Soweto, just before the 1994 election. The marathon was held on December 3rd, the International Day of Disabled Persons to raise awareness about the Disability Rights Charter, with aims of making sure that people with disabilities represented themselves in any forums where decisions would be made about them.

In order to study compounded vulnerability between misfit bodies and misfit environments, I was drawn to South Africa as my context for field work due to the country's experience of apartheid, and the brazen forms of debilitation, curtailed mobility, segregation and social exclusions enacted along racial lines, which represents another form of embodied difference. The legacy of apartheid has had lasting consequences for ever-burgeoning inequality, social fragmentation, unemployment and disinvestment witnessed to-date.[32] I also opted for it because of the explicit emphasis on post-conflict reparative planning processes since independence in 1994 and the promulgation of a constitution and bill of rights that is heralded as one of the most progressive in the world. I was curious to see where and how disability entered the conversation, especially in relation to other social justice priorities when presented with an opportunity to design the country's planning system from scratch, and that too in nascent history.

Given attendant questions of sovereignty, when thinking about profound disabilities, I was interested in seeing how individualized conceptions of autonomy are challenged by profound disability, and what examples of interdependent relationality might come into foresight by homing in on examples of it, especially in a living context, such as an informal settlement, which is not rigidly defined by individual property rights, ownership and thus hard boundaries. Given my own proximal experiences of profound disability in Karachi (another fragmented and highly contested urban context), and background of conducting research in *katchi-abadis*[33] there, I was interested in comparatively seeing what felt familiar and held true across Global South contexts and what was different and more situated. Johannesburg, the economic engine of the country, with a surrounding horizon visibly littered with historical debris of hyper-accumulation

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[32] South Africa has one of the highest rates of inequality ("South Africa" 2022).

[33] The term for informal settlements in Urdu. "katchi" roughly translates to "temporary" or "makeshift," while "abadis" translates to "settlements" or "habitations."

such as derelict mines and factories, mine dumps and slime dams, seemed to be an apt urban landscape to carry out this endeavor.

Figure 3: The carved wooden doors at the entrance to the Constitutional Court are eight meters high. They communicate the 27 fundamental human rights enshrined in the Bill of Rights, which are carved in every one of South Africa's 11 official languages. Picture of the doors' brass handle, which is inscribed with Braille.

A discussion on the significance of townships – the most obvious physical and spatial manifestations of apartheid ideology – is necessary to underscore the emergence of informal living settlements in the “neo apartheid” (Jürgens et al. 2013) era. The history of townships in Johannesburg is closely tied to the city's history as a center of the gold rush in the late 19th century. As the city grew, so did the demand for labor, and black Africans from all over South Africa came to work in the mines. However, they were not allowed to live in the city itself, and so they were forced to live in townships on the outskirts of town. The townships were designed as rudimentary dormitory style housing for single male laborers, lacking essential urban features such as public services, recreational facilities, industrial zones, transportation networks, and green spaces. These townships were intentionally separated from the white-dominant central areas, often achieved through the establishment of natural or artificial buffer zones. The guiding principle of segregationist ideology dictated the avoidance of any interaction or mingling between commuters of different racial backgrounds, representing a form of over-planning and attempt at over-determination of the urban spatial order. Consequently, one of the outcomes of this approach was the intentional geographical marginalization of these townships from the economic core and mainstream activities of the city.

In 1904, the Bubonic plague struck Johannesburg. The colonial city administration responded swiftly, building a team of contact tracers to go door-to-door and collect symptoms from people who had been exposed to the disease (Pascoe and Striplong 2020). They also asked neighborhoods with cases to self-quarantine and cordoned off a few neighborhoods to keep the ill from infecting others. However, the disease continued to spread, especially in urban areas inhabited by people of color. These areas were characterized by tight quarters and multigenerational households, which made it difficult to contain the spread of the disease. To address this, the city moved residents of these areas to isolation camps on the peripheries of the city, feeding a narrative that this fast and forceful action helped to drive down case rates and save many lives (Pascoe and Striplong 2020).

The isolation camp that was established in 1904 came to be known as Soweto.[34] Two years after the plague struck, the city forced all Africans into this isolation camp. The population's fear of sickness allowed the white power structures to take action that would have been hard to justify under everyday circumstances (Pascoe and Striplong 2020). In this way, apartheid in South Africa can be traced back to the seeds of a public health order designed to do

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[34] Soweto quickly grew to become one of the largest townships in the country, and became a center of political resistance to apartheid. In 1976, the Soweto Uprising erupted, when students protested against the use of Afrikaans as the language of instruction in schools. The uprising was brutally suppressed, but it helped to galvanize the anti-apartheid movement (Bonner and Segal 1998).

the most good for the greater public interest – eerily familiar to COVID-19 pandemic responses outlined earlier in this thesis, as well as some underlying design principles of UD.

The enduring legacy of apartheid's carceral control and segregation continues to shape the social and spatial dynamics of South Africa to-date. While legal strides have been made since the end of apartheid in dismantling *de jure* barriers and promoting equality, persistent spatial inequalities and limited access to resources and opportunities continue to disproportionately affect racially marginalized communities. Post-independence, emerging informal settlements – often interchangeably called "townships." Though different in some ordered characteristics, they are a product of rapid urbanization and growing economic inequality. In the city, xenophobia towards economic migrants from the African continent at-large has instead replaced violence in the public realm – who alongside poor black and colored South Africans, are often the primary occupants of these settlements.

Figure 4: Sculpture by Usha Seejarim donated to the Constitution Court Art Collection in 2020. The label has the following description: "The sculpture interrogates notions of home: as the country where one lives, the dwelling where one resides, the conflict or lack thereof, a sense of belonging, and the feeling of security or vulnerability of being at home. Two Department of Home Affairs signage boards, purchased from a scrap yard, are placed on an ironing board, an instrument synonymous with the home. The boards have special resonance for Black South Africans that required a permit to travel during Apartheid, severely limiting their freedom of movement. Today they are reminders of the plight of those who reside in South Africa from countries beyond its perimeters. The blanket placed between the boards belonged to a paraplegic woman in exchange for a new blanket. The woman was staying at the Methodist Church in Johannesburg in 2012, where refugees were given a space to live. She was not an

immigrant but from the Mpumalanga province. Her room was on the fifth floor that was shared with several other women and children, including her toddler. There was no disability access and no water. The inclusion of the blanket in the work is an attempt to find some level of nurture and coziness in contrast to the coldness of the boards and what they represent.

Slovo Park - A Profile

Figure 6 and 7: Photos I took at Slovo Park showing the sparse street layout and a typical homestead.

The fieldwork for this thesis was conducted in Slovo Park, an informal settlement located on the western outskirts of Johannesburg, directly south of Soweto. I was able to access the community residents, leaders and social workers there, through valuable pre-existing networks of trust cultivated over time by Professor Marie Huchzermeyer, who serves on a task team that has been concerned with long-term *in situ* upgradation plans for the settlement.

Named after anti-apartheid activist and the 1995 Minister of Housing Joe Slovo, the Slovo Park informal settlement was formed in 1991, and is home to roughly 3500 households and between 10-15,000 residents (SERI 2020). The land it is situated on is publicly owned. Overtime residents have started renting out shacks, not as owners, but as original occupants with a legal claim to the land having resided there for 30 years. As of 2017, approximately 1600 households were employed, of which over 98 percent earned less than R3500 (195 USD) per month (SERI 2020). In terms of basic services, about 3400 households have access to water from roughly 1000 taps (SERI 2020). Access to sanitation is facilitated through approximately 1000 pit latrines and 34 flush toilets and on average, 3-4 households (or 10-15 people) share a single yard-based toilet. Municipal electrification arrived for the first time in July 2018 (SERI 2020).

Two important features differentiate and characterize Slovo Park as an informal settlement. First is proactive collective action leading to the emergence of dedicated community leadership. This resulted in the creation of the Slovo Park Community Development Forum (SPCDF). In 2014, the forum successfully took legal action against the City for neglect and lack of development, and for proposing a resettlement plan that sought to displace and relocate residents (Ebrahim 2020). In 2016, the court ruled in SPCDF's favor and ordered the City to apply for funding and employ *in situ* upgradation approaches that are incremental and participatory (Cabe et al. 2018, Royston 2016, Ebrahim 2020). This successful outcome led to the provision of electricity for the first time in twenty years for the community and is the basis of the task team meetings for guiding future upgradation plans.

The second feature is the spatial orderliness of the settlement, with grid organization and very wide pathways delineating the rows of shacks. This can perhaps be attributed to availability of more land, given the extensive distance from the city center, helping mitigate densification. This can also be read as an anticipation that *in situ* development is expected and will eventually take shape (Huchzermeyer 2020).

3.3 Methods, Findings and Discussion

Research Design

From the outset my research was designed as a qualitative ethnographic exploration, given valence, affect and particularities of life with (the spectrum of) disabilities, and so semi-structured interviews and observations were my instrumental components. While the population subset my research was intended towards were people with PID, that was the very subset I could not include as my intended subjects, given issues around informed consent in order for this to qualify as an exempt study.[35] Instead I designed my instruments towards immediate care-givers for people with PID in the community, disabled people who could give informed consent (PWD), and community leaders and social workers in the community.

While I knew my overarching research questions, I was unsure how to translate them meaningfully for specific semi-structured interview instruments, and decided that at this early stage of the research, it was more constructive to have open-ended conversations about everyday life generally, and then tailor questions in the conversation to individual responses, as needed and pull out any interesting threads. In the past I have conducted interviews about specific policy or consumer interventions in a community, and so the questions in that research were also specific and parsed. Here though, this was difficult, because of the variegated nature of disabilities, even after narrowing it to one particular subset of intellectual disabilities. Furthermore, disability is not an emotionally neutral subject, and thus caution and care while approaching and prodding deeply personal experiences (in terms of the caregivers and PWD contingents, at least), and not being extractive or too pushy, especially as a complete outsider entering the community for the very first time, was on my mind. I intentionally decided to approach things from a place of restraint rather than urgency, and focus on building relationships, presence, respect and trust, even if that meant limited substantive information in the immediacy.

Even these issues and considerations point towards preliminary findings in terms of what a PFM approach cognizant of profound disabilities is going to mean. It was very evident that

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[35] Internal Review Board approval was granted by MIT’s Committee on the Use of Humans as Experimental Subjects (COUHES).

temporality, pace, particularity and relationality are incumbent to the process, just from research design considerations at this early stage of the process.

I made two trips to Johannesburg for fieldwork, paced about six months apart (June-August 2022 and January 2023). My primary aim for both was establishing trust for a long-term engagement. While I used the first trip to somewhat proactively glean insights in a systematic way, the second trip was made to build and affirm relationships and I spent my time revisiting my interviewees, mostly just to say hello and check-in, exchange candy and follow up, without a specific agenda of gaining more findings.

Overall, in my first trip, I interviewed five caregivers of PID, three PWD, and two community leaders, and one social worker. I also attended a weekly support group meeting that is organized at the Slovo Community Hall by the Gauteng Province Association of People with Disabilities (GPAPD) for everyone in the community with disabilities and their caregivers. Outside of the community, I conducted key-informant interviews with two academics Neil Klug (Lecturer, CUBES, Wits University) and Judith McKenzie (Professor, UCT), two NGO leaders Beena Chiba (GPAPD) and Richard Dobson (Asiye eTafuleni), and made complementary visits to the Constitution Court and the Apartheid Museum. Additionally, many informal conversations with Professor Huchzermeyer and members of Socioeconomic Rights Institute (SERI) also contributed insight. Next, I document some of the most illuminating observations and interactions below. These are interlaced with thematic discussions about the implications of the findings.

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CONTENT WARNING

Before proceeding further, I would like to indicate that some discussions below entail themes of sexual assault, neglect and suicide.

Field Notes

Planning to commute to Slovo Park from the city center was logistically complicated and expensive, given the distance. Most Uber drivers expressed puzzlement, and warned of safety issues, which was indicative of the kinds of perceptions Slovo Park, and informal settlements generally, elicited. One driver brought up a horrific incident that took place at a nearby mine dump a day before,[36] and expressed lots of concern for my safety. While finding a ride to go there was not difficult, getting an Uber driver to accept a ride for the journey back was a considerable challenge since most drivers openly expressed safety reservations about entering the community. Due to budgetary constraints, and expensive commute due to distance, I was able to organize four field visits in my summer trip to the community.

While the Uber drivers certainly heightened my safety apprehensions, this feeling was not unfamiliar to me, given fieldwork experiences in Karachi. Nevertheless, once I met Dan Moalahi, responsible for the communications portfolio of SPCDF, most of my initial anxiety dissipated and I was much more at ease. Dan asked me to meet him at the Community Hall, a partially open-air gathering space for the community. The Community Hall was established in 2010 and was a result of a participatory co-design process that emerged from SPCDF's partnership with a group of architecture students from University of Pretoria, and upgraded by the NGO 1to1 in 2018 (which was formed by some of the students participating in the immersion at Slovo Park in 2010). It is an emblem of the zest for change by the community and its leaders, and is not something I have witnessed often in informal communities in Karachi.

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[36] This incident is described in "80 Men" (2022).

[redacted]

Figure 9: Sketch of the Slovo Community Hall. Retrieved from: http://slovo-park.blogspot.com/2010/09/participation-of-university-of-pretoria.html

Dan introduced me to Makena and tasked her with helping me assist with my fieldwork. Makena is also proactively involved with SPCDF and administers and organizes various kinds of programming for the community, including a weekly community support circle for people with disabilities and those caring for them, in collaboration with social workers from the NGO GPAPD. She was well acquainted in the community and took me to various residences where she knew people with disabilities resided. It was initially hard to explain and request to prioritize meeting people with profound intellectual disabilities, so I didn't insist and instead let her guide the way to whomever she thought might be relevant for me to first speak to, since it might also be revealing in terms of who she envisioned me talking to.

Makena first took me to Lerato's house, a 38-year-old woman with scoliosis. She lives with her partner (unmarried), who also has a physical disability in his foot, and they have three children who also reside there. I am struck by how Makena just enters the premises to find them, while I wait for her to ask them for their time. She ushers me to come with her, but I insist she ask their permission first.

In our conversation Lerato indicates that she hasn't been employed since 2012 and was the only black person in a white office when she was working and had trouble there with acceptance because of her physical disability, which affected her self-esteem. Her dream was to become a lawyer. In 2010 she did a computer course, which allows her to be a receptionist or cashier.

She does not have assistive needs, other than needing a consistent supply of oxygen from her hospital for her weak lungs.

In my conversation with Lerato, she tells me that her disability grant from the government is their household's only source of income, and that everybody is unemployed. When I asked her about her everyday life, she said "all day I am just sitting around – it is quite boring. Doing nothing, watching TV, visiting my mother" but after being nudged by Makena, she indicates the gathering for people with disabilities which is held every Wednesday, where they "talk about life experiences, things we need."

Regarding the grant she says it "...does nothing. The food cost is rising. The grant is 1980R per month. 980 goes for transport – what do I do with 1000 for a whole month. We take a taxi, or ask people in the community to go somewhere, but it's money. Tomorrow I'm going to the hospital and he charges me 350R for that. The government does nothing."

Regarding community support she says “No community support, not here – everyone for themselves” and that her neighbors treat her well “...but Slovo is so big – if I go to the other side then people wonder who I am. But not on my side”.

I ask her how she and her partner met. She laughs and says “a friend, who I grew up with, invited me to see him. I went after she persuaded me. My cousin was like you must go and get a boyfriend. My cousin was teasing me and saying you need a boyfriend and you need to stop sulking here. Then I went to see my friend and stayed the night. And she invited her guy friend and I’m like no, I'm not here to go around, I’m here for you. But then I stubbornly went and this guy was there. Then she’s like ‘look, he has a cute smile’. After meeting him she gave him my number. I don’t want guys, I don’t want to talk to him. My cousin encouraged me to talk to him. So, I did and he said he liked me. We had lunch and everything and then it started.”

I was a little frustrated with myself, after this first interview, because it felt like Lerato did not have significant assistive needs – at least none that came forward within the parameters of my conversation with her. I wondered if I was unable to tease out the spatial/material-discursive misfit encounters and challenges, at least in any useful detail, of living in this community and environment with a disability, and questioned if my methods may need to be more time-immersive and observational in the future. I was also surprised to learn of a disability grant that almost seemed to supplant household income, which also led me to question if I had picked the right context, given the apparently substantive welfare mechanism (relative to Global South contexts) – and how “normal” and everyday Lerato’s life seemed to be, unmarked by any drastic and extraordinary consequences because of her disability, at least through this first ephemeral conversation. Lerato did have an extraordinarily visible disability, and disfigurement because of it, despite no significantly apparent assistive needs, and it is interesting to note that

Makena took me to her for conversation, as the first relevant case that came to her mind in this regard. Lerato was educated and could also converse well, and name and discuss her medical condition, so maybe Makena thought that this would ease my research. Nevertheless, it is interesting to document this, since under the full ambit of "disability," apparent and extent of bodily waywardness and appearance is what immediately taps sensibilities in our first encounters of trying to analytically engage with it, and as evident with Lerato's case, this does not necessarily translate or equate with the levels of vulnerability, assistance and *anormative* care that is required and needs to be prescriptive to individual cases.

When I visited the community in January, Lerato had passed away only a couple of days prior to my arrival, due to health complications. It was too recent for me to inquire and ascertain with her family if situational and environmental barriers had a significant role.

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My intention with reproducing my first day of fieldwork Lerato's account above and Cara's account next, in considerable detail, is to highlight the differences and magnitude of stakes, in relation to vulnerability and scarcity of care, in this context, when honing in on profound disabilities explicitly.

After completing Lerato's interview, I asked both her and Makena for examples specifically of people with profound intellectual disabilities and their caregivers in the community, and they both suggested I visit Cara's house.

As we were approaching Cara's house, Makena said to me that we will only go here briefly and then go somewhere else, which slightly puzzled me and made me anxious about gate-keeping on her part.

When we entered the lane for Cara's house, a group of women from neighboring shacks started gathering to see who had come. When Makena indicated to them that I was here to see Cara's "caregiver", it felt like something ruptured. There was a charge in the air and they started talking loudly over each other. As Makena leads me to Cara's house, one of them angrily approaches me and asserts that she is the caregiver and that I should speak to her. I tell her I will come to her, but she still hovers as we approach Cara's shack.

Cara is there, and her 19-year-old sister, Michelle, is around. But the mother is away for work. Cara is a 20-year-old, small, skinny, and friendly girl. She is playing with coloring books in the yard space of her shack. Observationally I suspect she has a milder form of cerebral palsy, with an intellectual age equivalent to a five or a six-year-old. Makena requests her sister to talk to me, but it is a rather cursory conversation. The sister indicates to me that they are a total of six siblings and that they live in their single room shack with their mother. The father passed away in 2017 due to a heart attack. She indicates that other than the mother, nobody is earning. She doesn't know the name of Cara's disability but she says that she does have seizures.

I ask her who takes care of Cara and she says that Janelle auntie does, the lady who is hovering nearby. She adds "Cara likes to go and sit near her house so she decided Cara can go there every day, so that she doesn't wander elsewhere. It's not safe for her on the streets. She liked her and they became friends. Cara likes to meet people. She is a people's person. Cara eats here and there. She eats a lot actually."

She indicates to me that their mother comes back at 7pm on weekdays, 4pm on Saturdays and doesn't work on Sundays.

Her sister's inability to name the diagnosis was a repeated problem I confronted during fieldwork, across families, and often had to resort to asking for medical records since this wasn't easy to ascertain from observation either. I went back for Cara's record later in my fieldwork and ascertained that it in fact was cerebral palsy. The issue represents another problem – the complicated medical terms, and the lack of ease afforded when trying to communicate about, or even personally register in memory, the specific condition of disability despite familial proximity. This challenge represents a subtle but consequential form of exclusion from the public realm. On the other hand, it may also be a finding complicating the assumption imposed by us as researchers in our questioning, that (profound) disability necessarily registers as a "medicalized" diagnosis for families and kin, or even if it does so, that medical system is very likely stiffly out of economic reach, and thus, alien. It may also mean that, given the context of informality, and the extraordinary environmental and infrastructural debility faced by all its residents, these specific categories for particular members in its fold are exhausting and meaningless. And thus, the framing of a "disabled" environment for informality becomes relevant.

I then approach Janelle and walk with her into her residential space. I can sense a little unease from Makena around this. I was also worried about my decision, since I did not want to inadvertently exacerbate a tense situation concerning a person with an intellectual disability, but I also did not want to ignore a potential caregiver for the integrity of my findings and arguments.

Janelle is a 39-year-old woman who is not working at the moment, and moved to this area recently, three months ago, after losing her job, since she couldn't continue to afford the rent at her previous premises. Regarding Cara, she says that Cara started coming to her place. She says that she was friendly, but she could tell she was disabled. Very soon she realized that it was "a deeper need." She says "when she first used to come by, she asked for tea. Then she started coming every day and I noticed she was not bathing. I started bathing her without her mother's concern, because I heard on the street that her mother is working. I never went to the mother to approach her, I wanted her to approach me to thank me for taking care of her daughter. She never came. That is how our relationship started. If Cara is not at home, her brother and sisters know they can come find her sitting here."

She adds "...and now I have a deeper problem. Her medication is finished. I am begging and pleading with her mother to give me money so I can go fetch her medication. But now I look like the demon. Yesterday the social workers were here. When they came for a home visit, I had to fetch her. Cara was excited because she hadn't seen the social worker in a long time. Cara even said to me to "come, I want you to see my social worker". In the evening when the mother came it was chaos. The mother wasn't happy." She adds "I will keep Cara until her mother comes. I won't leave her in Michelle's custody. I won't leave her with Angela (another sister). She must be present when she takes Cara from me. I must know she's at home and she is now taking care of Cara. Last night she came in the evening, and Cara was already fed and already ate supper. It was just for her to fetch Cara. She came, she knocked, she never greeted me. She came with an attitude towards me. "

I ask her about her own children. She says she has five girls and three boys. Three of the girls and two of the boys live with her, and the rest are with their father. She emphasizes that she has enough time to take care of her children because she can't go to work right now because of a nine-month-old baby. She emphasizes that taking care of Cara is not a problem but she adds that "I am doing the washing. I am cleaning Cara. I am keeping Cara clean. And I didn't ask for a cent from her mother."

I ask her about her household income, and she indicates that one of her daughters is bipolar and is receiving a disability grant. She is also receiving the children's grant. She says her partner and her are not together anymore. He is not supporting her because he is in "more" debt. She sometimes receives support from her sister. I ask her about her daughter's care needs, and she says she is perfectly able to take care of her, and that the daughter is doing well at school.

Given that there seems to be clear conflict around meeting caregiving needs for Cara, indicative of scarcity, erosion of care and trust, and a stretching thin of kinship ties, as conceptualized earlier, I ask her what she thinks would be the best support for this community, in terms of care needs like those of Cara's.

She states that they really need frequent visits from social workers and adds that "they should come in once or twice a week – just to see if the family is fine. Now social workers come once in a blue moon and don't keep track. In this community, they (people generally) take advantage of children with disabilities. Even my daughter, she is turning 17, if you go out, I don't want you far away from home. And I want to know her friends. I can't keep you away from going out, but you must have self-respect. And nobody can touch you. I also tell Cara if somebody touches you where they shouldn't, you must tell auntie. Which is why social workers must come to this community. They have to be strict with boundaries – cause in this community some families take it very lightly."

She adds "I don't care what they say, can you please talk to Daniella's children? This is on my heart. This morning Cara came over, she comes every morning. Cara is wet, makes bed-wet. In the morning she is wet and they let her be like that. Today Cara changed herself and didn't even have underwear on. When I speak to them, they start shouting at me." Makena asks her to come to the community support meetings.

Janelle goes on “I am having a hard time talking to the social worker and the mother. She is making me the demon, I am bad. Only thing I want for Cara is the best. To be clean, to eat and to have her medicines. Asking for her medication…chaos, my sister.” Makena interjects and says that Cara was also raped recently. I am gutted to hear this.

Janelle continues “Cara is twenty, and will go out [of the house]. When she goes [to work], her family relaxes. Me and my daughters are out late looking for Cara. They don’t take good care of Cara and it is breaking my heart. Cara doesn’t have underwear. Things that a young girl must have [starts crying]. Cara is getting money from the government. Her mother doesn't buy toiletries for her – I am doing that. Cara had her period three weeks ago; she was full of blood. Nobody buys. They skipped the injection (birth control) – I had to ask, cause I don’t know which days the clinic is organized. The mother is checking me and telling neighbors that I want Cara’s disability (grant). I don’t want Cara’s disability [grant]. I took care of her without the mother’s knowledge. I just felt – if I can take care of her, she is the one that is better.”

After talking to Janelle, I thank her, and I start walking with Lerato back to her house as Makena stays to chat some more. Before leaving with Lerato, Makena, I think after noticing how impacted I am with this account, mentions that there is another hair-raising case, where a pregnant woman with intellectual disabilities is apparently kept locked in her shack to prevent her from wandering in the neighborhood. We agree that we will try to visit her during my next trip to Slovo.

Cara’s case instantly dispelled my earlier doubts that day about studying the wrong context. It also made me acutely aware about the outward differences in terms of vulnerability between her, a person with a profound intellectual disability and Lerato’s case. Her situation is evidently affected by multiple socio-political pressures argued earlier, and a weighty manifestation of the threat to care and kinship ties. This points to an unmistakable need for planning to explicitly focus on the needs of this faction and confirms the need for articulating a planning for the margins framing of vulnerability, adjusted through a planning for care approach.

On the walk back, Lerato says that the mother gave Cara's disability card to loan sharks to take out loans for beer. And that everybody here is taking care of Cara. Not just Janelle. She adds "Cara needs support and care. The guy (loan shark) is not wrong, who she (Daniella) gave the card to. When you are unemployed, there are many ways to make money. The mother owes a lot of people."

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In my past experiences of fieldwork, it has usually been necessary to prod repeatedly in order to arrive at a point that leads to valuable information regarding the topic of interest. This was the first time where my mere presence at the doorstep and stated research intentions elicited so much outpouring and overwhelming affective response towards a clarifying question to merely determine my respondent: who is the caregiver? It also made me think about the lack of outlets for such a situation, even in imaginaries of disability studies, and the extent of erasure that led to an enormous bubble being burst, for release, at possibly the first hint of curiosity.

With the advice of my thesis advisor, I resolved to try and speak with Cara's mother that Sunday to get a fuller understanding of Cara's situation and to try and get both sides of the story. I asked Makena to invite her for an interview that Sunday morning at the Community Hall, instead of her residential lane, where there was no privacy to conduct isolated conversations.

On Sunday Daniella arrives promptly at 9am and I notice that she is dressed well. I obtain consent. She then tells me she is 42-years-old and has been back at work for the past two and a half months, where she is a sales lady for a company that sells curtains and fabric to make clothes. During COVID she was out of work, and her sister-in-law helped her out financially during that period. But she was recently called back to work. She has a total of six children. She has lived in Slovo for 14 years, and moved here from Eldorado Park with her children's father, who passed away four years ago because of a heart attack. She was still working when he was alive and he was unemployed. She earns 3000R per month. Her eldest is 23 years old, Cara is 20, and she also has a 17-year-old, a 12-year-old, a four-year-old and a baby that is one year and one month along. The youngest has a different father, who is around and helps support the baby. I ask her about Cara's diagnosis, she is unable to answer that, so she tells me her medication instead.

She tells me about Cara's childhood and when she noticed the first signs that there was a problem. Cara was two-and-a-half-years old then. She says "She got sick on a Thursday night. I woke up at 4 am and told her father I didn't sleep with Cara and I need to go to the hospital with her. Cara was shaking. I didn't know what was going on." After another bout of sickness, the hospital staff told her that "the child is paralyzed." She says this was a confusing time. When Cara turned five the hospital staff told her that Cara should start going to disability school. She says "I didn't know what disability is then, and found out it means you can't do things on your own." She says that she usually has to struggle with sending Cara to school and often has to bribe her with one or two Rand.

Her early struggles and confusion points to the issue that often parents raising children with special needs lack the full support they need to address these challenges. Existing support for families with special needs often concentrates on the children, leaving the crucial needs of parents, particularly caregiving mothers, unattended. During the initial stages of grappling with a diagnosis, parents can encounter profound emotions of grief and persistent sadness, coupled with substantial educational deficits regarding preparedness for distinct childcare needs, and this necessity remains unnoticed and erased due to the absence of a care infrastructure.

Daniella underscores familial tensions with her children and says that her children (other than Cara) only view her as their mother when she has money to offer them. She says she has problems with her eldest daughter and that when it comes to payday, the daughter takes the disability card and the children's card to pay back people she owes. She says she has involved the social worker over this and has even considered calling the police. She mentions feeling unsupported by her children and that she goes to work every day and comes late, but when she gets home, not only must she also clean and cook, she also has to go look for Cara in the neighborhood.

It is apparent that not only have neighborly and kinship ties been stretched thin, family ties, too, have been tested and buckled under perpetual and never-ending pressure, due to the overburden created by Cara's condition in a profoundly resource-scarce environment, with no planned infrastructure of support or care that can help manage and circumvent the everyday nature of the crisis that is engendered for their household. I am reminded of my brother's condition in some ways, where, given the everyday and perpetual nature of catastrophe created by his elevated needs for caregiving, and with no designed incentive structure in place to help provide them, the endlessness of the situation often all but requires you to numb your own empathy, in order to continue being functional and keep up with everyday demands and functional appearances of participation in civic life. It points to the finding that in order to provide good and sustained caregiving, caregivers also need to be cared for.

About Janelle, Daniella indicates mixed behavior. She says “Last week when I came home from work, I started cooking. The aunty across said you have useless children. On Sunday the neighbor came and said my daughter Michelle was yelling and pushing you around, and I said just leave it. And then she yelled at Michelle saying you people want your mother dead. Your father is already dead and she is suicidal because of you. And then she said to them to let me kill myself. I was just sitting and saying nothing. I told Janelle to just leave her.”

She laments that Janelle easily switches blame and accuses her too: “She comes and says why does she have to bathe and look after Cara, when she is not her child. This other lady pretends she looks after Cara. But now she likes to talk shit too. Who told her to go buy things for Cara? Cara has her own things. She wants to tell the social worker that she is the one looking after her.”

Her involuntary and non-preferential dependency on Janelle, has created a sense of entitlement for Janelle and a power hierarchy, where Janelle can feel entitled to assert this to her in ad hoc and imposing ways – again pointing to a need for a carefully designed infrastructure of care, that can mitigate tensions like these imposed on kinship ties, or one which endeavors to empower and repair them in a way that is equanimous. It underscores Binet et al. 's (2022) conclusion that alleviating and equitably distributing the burden of care work by expanding caregivers' freedoms to give and receive care in ways they value is imperative, and also fostering a diversity of possible forms that care can take.

Daniella indicates that the impossibility of her situation, where she has to choose between protecting or providing for her daughter has led her to feel suicidal: “Even today I was thinking I need to kill myself. I was like let the social worker [Daniella assumed I was a social worker] come. Let me tell them my story and then let me go to the highway. I am done.”

We pause, and I am unsure how to proceed. Her indication of feeling suicidal in a research interaction makes me wonder what are/can be boundaries of intervention and help as planning and participatory action researchers? And how can I make honest claims of being invested in relationship-building and trust, if I cannot intervene to help, despite privilege?

She adds “My thing is I want Cara away from here. At night when I come after work, I can't even find Cara. Others (her other children) are sleeping except for her, and I must now go look for her. Because if something happens, they will come for me – “your child is raped”, “your child is dead”, it is my problem, they are sleeping. How am I supposed to feel when I come home and my child is not there. They don’t bathe my child; they don’t give food to my child. They don’t do nothing for my child [starts crying]. Just now something happened to her when I was not at home [referring to the rape]. It's going to happen again, because there is no one. My children don’t care about Cara. The culprit is in jail now. We called the police and opened the case. He is going to be away for two years.”

I ask her about managing expenses and she says that when she wasn’t working, they were able to manage on income from the grant, which enabled her to cook three times a day. She says “But now, I have to work and also cook when I come back from work because they (her children) don’t cook during the day. When they have money they buy chips, but they don’t share with Cara, which is so wrong because it is her money. I cook with that money, I pay rent with that money. The rent for my shack is 500R. I have my cards. I have Cara’s card, not the other [the children’s grant] card. We don’t get paid at the end of the month. Auntie (a different neighbor) is looking after the baby and I pay her 1000R each month, and I buy food. And toiletries for Cara and things she needs. Things are expensive now and whatever is short. I buy…everything…pads. Though now she doesn’t get periods. I bought nice underwear and my other daughter was fighting that we didn’t buy it for her.”

I am struck at how the disability grant is an important mechanism to supplant income, given pervasive unemployment in South Africa, in all three households I have visited so far. I ask her about Cara’s medicine provision (generally, without alluding to Janelle). She said they are usually able to get them on time except for last month, when her daughter told her the appointment was on the 17th, when in fact it was on the 14th when they opened the card to check. She adds “I stayed absent [from work] for no reason and they will now duck 200R from my wages for no reason.” She says Cara is supposed to take medication in the morning and at night, but because she is still sleeping in the morning when she is heading out for work, she administers it to her at night.

This example points to the precarity that is engendered by punitive workplace mechanisms and incentive structures not attuned to the magnitude of vulnerability in a household with a person with profound disability.

I ask her about what kind of relationship Cara has with the neighbors generally. She says “the neighbors like Cara. But Cara is so naughty. She will sit down for five or ten minutes and then disappear. Goes and says ‘Hi’ and ‘Hellos’ with everyone. She likes men too much also. I told the social worker before. I'm so scared for Cara. That she might get pregnant and then it's my problem. Because any man can go sleep with Cara, because she doesn’t know who the boyfriend is. And tomorrow I will have to go to jail for her because I can't take care of her. I want Cara out of here. Please take her away, if you can”

This again points to how values of individualism have eroded trust and community ties between neighbors and created risk and precarity that is compounded for Cara and her safety in this environment. The prevalence of loan sharks in the community is also indicative of this. It is important to reframe these valuable community ties through interdependence and collective ideas about autonomy for restorative approaches to strengthen kinship and care, especially in a situation like Cara's where rigid ideas of both, bodily and territorial sovereignty, are in flux.

I ask her why did Cara's period stopped and she indicates her period stopped because she is on prevention. She says "Cara will say "everyone is my boyfriend, friend, uncle." They will give two Rands to her and sleep with her. Every day they face me and then they are raping my child. I immediately went and made a case [against the rapist]. To give a message. My child is not normal."

I asked her what her relationship now is like with the family of the rapist. She said the brother of the culprit was on her side and agreed this is wrong and they are on good terms with the family.

At the end of this conversation, she profusely thanked me for listening to her and said "I talked my heart out. I'm free now."

Lastly, I asked her for her opinion regarding what would be most helpful for her situation. She said she wished there was a place to keep children like Cara busy and in one place, where she could be certain she is safe. She adds "I know there is no money in the world. But we must try. She can't count to ten but I want to teach her. Maybe something like that can do that for her".

When I visited again in January, I was unable to meet Cara because she was hospitalized at that time due to seizures, on her own, from what I could briefly gather from her sister. Her mother was at work and neither was Janelle around that day. I left some candy I had brought for her with her sister.

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I wanted to provide a detailed portrait of Cara's situation because it is at the heart of the argument for this thesis, and will discuss the implications below. I also kept Lerato's account to offer a comparison and contrast between my interactions with a case concerning a person with profound disability and a person with a disability who can still provide informed consent. But before I move to further discussion about her case specifically, I do want to summarize findings from the rest of my fieldwork too.

In addition to Cara and Lerato's interviews – I did four more interviews of either caregivers or people with disabilities who could provide informed consent.[37] Two of them were caregivers for people with profound disabilities, and I summarize them here because this thesis concerns them specifically – Makena herself spoke for Taneko, a girl she was supporting in the community. She couldn't tell me what Taneko's disability was or her age, and Taneko was silent in my presence and I couldn't ascertain much observationally about her ability to provide informed consent or engage in conversation. It was also difficult to manage Makena's sometimes paternalistic approach and deficit-framing of Taneko, when describing Taneko's situation in Taneko's presence, and this is another challenge for fieldwork of this sort. Makena indicated that Taneko was the pregnant disabled woman she was referring to, but Taneko was moving about in the community and did not seem locked up or restrained as Makena had implied earlier.

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[37] Though this was also tricky to ascertain from the outset, especially when endeavoring to operate without making quick assumptions.

Taneko lived in a derelict shack, which Makena had arranged for her. She was pregnant at the time and Makena told me that the social workers had promised to take the baby away after her delivery, and to sterilize her after that, because “she is suffering”. She is a migrant from Lesotho and therefore not eligible for the disability grant in South Africa. Taneko was raped in Lesotho and became pregnant. She was living with her grandmother there, and according to Makena, the grandmother had a heart attack from stress. She became alone and came to South Africa because her mother is located here, but they have a nonexistent relationship.

When I visited again, Taneko was still up and about in the community. She had given birth and her baby had been taken away by authorities into the foster care system.

In addition to Taneko, Makena introduced me to Sanza’s mother Abena. Sanza, it was evident, has some form of PID – he is unable to talk coherently or walk, and has seizures, according to Abena, but Abena was unable to tell me his diagnosis. He is nine-years-old and Abena is 52, and his primary caregiver. Their household income is sustained through his disability grant and she is unable to go anywhere without him. She said the father is no longer around. She has another 20-year-old son, who is not very helpful. In terms of challenges, she says that when it's raining, she can’t walk with the wheelchair in the community. She also doesn't have a bathroom, and she bathes him in a tub. He is growing and getting heavier and she gets tired of carrying him. And since he is only going to get bigger, she is uncertain what this is going to mean in the future. She also says diapers are a huge problem, because the ones for his size are not always available.

In my second visit, Abena was still very stressed about the difficulty of sourcing adequately sized diapers. This points to how, again mass-produced consumer products catered for the largest majority, create dire situations of misfit and again, the need for designing for particularity for this faction or amplifying embodied personnel care. Abena had moved with Sanza from her previous shack to a rented one some distance away in the community. Makena separately told me that this was done to get away from her other son, who had become violent towards her. The complete absence of male familial figures in any role of support, in all my cases of profound intellectual disability, is palpable.

I also attended the Wednesday community gathering, which partially also served as an FGD. I also had a chance to speak with Jones, the GPAPD social worker serving this community. The community gathering was an incredibly warm and supportive space. It was held inside a small container that serves as an office space next to the community hall. I settled in at the very back, and slowly the container filled up with people, and everybody was sitting shoulder to shoulder in a circle. Tea was passed around, and people were sharing food and feeding each other with their hands. Before commencing, the gathering sang church songs together, which instantly eradicated any ice, and I found myself (somewhat romantically) wondering, what would change if every gathering in the world started by singing together. I met other members of the community, who I did not get to interview as part of my fieldwork, and Jones asked everyone to introduce themselves to me and share some of their history and challenges they face. This included examples like negotiating salaries in the corporate sector, which reduces pay based on the assumption of income being supplemented through the disability grant, subjective and ad hoc assessment of hospitals to ascertain qualification for disability grant, and long waiting periods for the disability grant. After that gathering, I had an individual conversation with Jones, learned about GPAPD and consulted him on Cara and Taneko’s cases, since neither of them had stable caregivers and family ties.

Jones struck me as closely aware of both of their situations. He had brought rations bags for the two of them specifically and diapers for Sanza. He indicated that the consideration of institutionalizing Cara was on the table, if in case her situation did not improve. When I met him in my second visit at the GPAPD office, in my second visit to Johannesburg, he told me there were plans in the near future to move Cara to Eldorado Park so that her grandmother could take care of her.

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Next, I move to discussing some of the implications of this fieldwork. They are divided across the themes and questions that emerged for me.

Neoliberal Choices and the Burden of Impossibility on Women

It was significantly unsettling and alarming to learn that the only protections in place against sexual violence for a female individual with profound intellectual disabilities was birth control or sterilization to avoid pregnancy, and that this is at risk of being quotidian. As evident, there is an overextended, untenable economic burden on women as breadwinners and caregivers – due to household unity as an institution being long-lastingly destroyed as a result of apartheid, and this was compounded with the spread of HIV later.[38] Judith Mckenzie, associate professor of disability studies at University of Cape Town, in my interview with her for this research, said she would also add the birth of a child with disability leading the father to leave, to that list of reasons. How can planning be cognizant of these outcomes at community and household levels and play a preemptive role?

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[38] See Hall et al. (2022) for more on this.

Richard Dobson, founder of Asiye eTafuleni – an NGO in Durban focused on developing inclusive urban spaces that support sustainable livelihoods for informal workers, in my interview with him, indicated that at least in terms of child care, “proximity is all what it's about,” describing his work for WHO which focused on health issues and promoting breast-feeding for the first 100 days after birth. In order to facilitate this, his organization is designing daycare “pop-ups” on the streets for female informal workers in Durban. This may hold for normative childcare, but I am unsure the complexity and differentiated needs of people with PID, and the vulnerability engendered, can end with proximity as the only solution, without structurally alleviating some of the responsibilities of this impossible double-burden faced by women.

Figure 10: Photo of the female domestic labor uniform from the colonial and apartheid era that hangs in the Apartheid Museum. The pins around the breasts signify the painful history of subjugation and exploited femininity and care

Care Possibilities and Foreclosures

Figure 12: Photo taken by me inside the container office space where the weekly disability support group meetings are held.

While it is difficult to presume or discern motivations for Janelle's or Daniella's accusations towards each other, there *is* a display of anormative care by Janelle in her concern and intervention in terms of caring for Cara. And this form of care, kinship and rescue is hard to imagine in contexts dictated by rigid boundaries, property rights and ownership. Meekosha and Soldactic argued that rights are a shaping mechanism to guide behavior in industrialized societies, "whereas non-metropole cultures have distinct traditions of emancipatory and collective struggle" (2011, 1388). Property rights and ideas about ownership are also a feature of industrialized society. Is something foreclosed by an unquestionable emphasis on bodily and territorial sovereignty, when a disabled environment meets a disabled body? Or can there be generative exceptions?

This was also displayed by the ease with which Makena entered all the various homes, and where the occupants also did not take offense or feel threatened by that. Professor McKenzie, in my conversation with her says that “there are advantages to framing it (care) as a relational concept, instead of opposing rights, the rights of the parents or the rights of the child, which is such a problem when we’re talking about PID, when the rights of the person are being seen as separate, whereas that relationship is critical to sustaining relationships, and that needs to be nurtured.”

The support group meeting, and witnessing the community sing together was also such a moment of affirmation and care, where neighbors were feeding each with their bare hands, without that being seen as an infringement. Growing up with my brother in a high-income development of Karachi, this was foreclosed to us – there were no such avenues to experience this kind of camaraderie pertaining to my brother’s condition with others in our neighborhood (or otherwise) facing similar challenges. And there was no community.

These examples can also be constituted as “spatial practices of informality” (Kudva 2009, 1614) and they embody the converse of causing “impairment” and maiming. And these examples also beg the question whether something for care and kinship is foreclosed at risk by formalization or upgradation of informal settlements? And can attention be cast on ways to preserve this critical, yet invisibilized feature, as part of those processes?

Who is the Spokesperson?

Figure 13: Photo of a boy sitting on a couch outside of his house next to his wheelchair

In contested situations, just like the challenge of ascertaining who the caregiver is, we also need to wonder who is the spokesperson for people with profound disabilities? In Cara's case, it is not straightforward and evidently hard to discern this. Who should receive the grant money? Is it in Cara's long-term interest for parental and familial relationships to be prioritized and preserved? Or can we deploy examples like these as opportunities towards thinking about what might it mean to replicate caregiving informed by primacy of family ties in the public realm? Should there be a case for family abolition and reimagining meaningful care structures outside of traditionally imagined ones – and maybe attempt to move care from the private realm and into the public? Or do we assist and augment the family as a key social and political unit, with incredible enduring power, even though it has lots of permutations and nontraditional forms. Can private lives be protected but also bridged to their public forms?

This also represents a need for articulating a temporal approach – as researchers, if we can spend more time and approach research from a relational purview, we may find better answers to these questions for someone like Cara. This has implications for thinking about participatory action research approaches, and the contingency of communicative planning, which to date also assume abilities around self-advocacy and self-representation.[39] [40] Can we ask what a participatory *in situ* upgradation process means which also accounts for people with profound disabilities?

Pace, Worth, Work, Welfare and AI

Figure 14: Photo of a liquor wholesaler sign seen in Slovo Park.

Precarity creates space for unbridled proliferation and catastrophe – this has been obvious from recent examples such as those of the global pandemic, climate induced urban flooding, and most recently, questions for the future of work through the advent of generative AI. Rapid growth without development creates "waithood" [41] and informality. And premiums and impetus for speedy mobility through neoliberalism creates a diminished and deficit casting of disability.

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[39] Though some frameworks trying to contend with this are emerging. See Natarajan (2017).

[40] Interestingly, through desk research for this project, I learned that Habermas had a cleft-lip, which informed some of his approaches to communication theory and the importance of dependence and vulnerability (Welton 2020).

[41] Waithood is described as "young Africans struggling with unemployment, the difficulty of finding

Garland-Thomson says “the concept of shape carrying story introduces temporality into encounters between body and world, in a narrative that by definition connects moments in space into a coherent form we call story. The idea that shape carries story suggests, then, that material bodies are not only in the spaces of the world but that they are entwined with temporality as well” (2011, 596)

Profound disability offers us a temporal framework[42] through stillness and pause, creating temporal space for affect in praxis (Thrift 2004), and a justification for pulling the brakes. A care infrastructure that is attuned and premised on misfit vulnerability will empower the exercise of those brakes. A PFM approach for people with profound disabilities necessarily divorces the tying of human worth with human capacity and individualized autonomy, allowing us to plan for interdependence and relationality — and these frames are central for approaches that are interested in structurally addressing the climate crises, reimagining work with advent of AI and future pandemics, as has already been argued.

Yet, there is another (suspected, but unconfirmed) insight from this research, which I think can inform discussions on global AI proliferation, unemployment and welfare. We have seen through this research how state welfare in service of accumulation can create contestation. But has it also led to the creation of troublesome incentives? It was anecdotally suggested to me by one of my Uber drivers that “colored” women in townships will sometimes intentionally drink during pregnancy, so that they can give birth to children with fetal alcohol spectrum disorders (FASD), which enables them to qualify for the disability grant to supplant household income, given pervasive unemployment. He said this as a colored man who lived in a township. While I

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sustainable livelihoods, and the absence of civil liberties” (Honwana 2013) leading them to “improvise livelihoods and conduct their personal relations outside of dominant economic and familial frameworks” (Honwana 2013).

[42] Usually termed “criptime.” For more on this see Kafer (2013) and Samuels (2017).

could not find any research to confirm this, there are some news articles (Crawford 2013) and counter news articles (Cunliffe-Jones 2013, Full Fact 2013) that suggest a discourse, and there is a noticeably high rate of FASD for South Africa; a prevalence at 111 per 1000 children, 14 times higher than the global average of roughly eight per 1000 (Hodal 2018). This can also, unsurprisingly, be traced to apartheid and colonial legacy, where a culture and reliance on alcohol was cultivated by white settlers through a "dop"[43] system, to use as a deliberate form of social control over black locals, and adds to the broader history of a politics of impairment that need greater recognition within predominant disability discourses.

If hypothetically this is in fact a phenomenon, we are witnessing an intentional and proactive production of disability, which raises some intellectual wrenches in need of modulation, especially by the social model of disability.[44] But aside from this, given the trajectory of AI replacing work with global consequences, this bodes the question: will there be an increase in demands for disability welfare support in contexts around the world?[45]

A PFM assemblage premised on disability justice can help reimagine work and care, where even if generative AI is able to replace work, we can create spaces of occupation for people in the attendant maximalist infrastructure of care, proposed within this PFM framework. Care, especially as affect and interdependence, fundamentally requires embodied human interaction and connection, and there can never be AI substitutes for that.

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[43] See De Jong et al. (2021) for more on the Dop system.

[44] Even if these wrenches are fictional in this case, there are other examples of them in the world – such as the phenomenon of intentional amputation to create spectacular disability for begging purposes in urban areas across Pakistan, or the phenomenon of "choohas" at Shah Daula shrine in Gujrat, Pakistan. See Miles (2010).

[45] I must credit a conversation with Anisha Gade for sparking this connection.

Conclusion

“Nobody truly knows a nation, unless they have been inside its jail cells”[46]

“The places where disability meets the built world are generous and generative”[47]

When informed consent is troubled by the researcher’s communicative challenges, what might a research interaction mean with subjects with profound disabilities in terms of understanding their social context, in deeply contested settings? It took me back to the Peabody-Smith quote we used in the opening. It would mean spending lots of unstructured time, understanding cues, and feeling comfortable enough to make and trust decisions on somebody else’s behalf without full insight of wishes, but with intuition (and with means for gaining some confirmation that researcher’s translations are correct), affect and sensitivity – tying their interest to your own i.e., interdependence. It might mean participatory action research, and enabling caregivers as resident researchers – or for researchers to see themselves as caregivers, I don’t have a sure answer yet, but through this thesis, I think I have showcased the importance and stakes of thinking through these issues and figuring out best practices that enable democratic processes, predicated on assumptions about autonomy and self-representation, to evolve their capacities to ensure informed human-centered planning.

Cara and Taneko’s cases show that the lives versus livelihoods quandary, amplified and universalized during pandemic times, is not episodic to catastrophes, but in fact an everyday lived reality faced by some who are very much a part of our shared urban fabric. Planning that can alleviate untenable situations faced by these factions, may provide answers that protect all of

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[46] A quote I remember reading on the entrance of Prison Number 4 at Constitution Hill. I can’t recall who it was attributed to.

[47] Hendren (2023)

us, and effectively equip planners in more resilient ways to face these quandaries, when they do arise in the face of planetary-scale crises –- by addressing the problem of dignity in global social contracts, especially when the go-to decision matrix defaults under pressure to utilitarianism and tacit measures of personhood via economic worth.

This exposition ties in seemingly disparate examples of planning for the largest majority; utilitarian pandemic crisis approaches, universal design or spatial apartheid practices to articulate a common thread of exclusion often justified in service of the greater good, but one which is not compatible with articulations of justice itself. The cases highlighted in this study, underscore the importance of conceptualizing care as the common denominator, moving beyond universal design the panacea in planning for disability and creating space to define access also as "access to kinship." Care can be an ethic and an outcome, and this allows us to plan for transitional, as well as transformative justice through it. Binet et al. (2022) demonstrated that care is spatial and a necessary concern for urban planning. Focusing on people with profound disabilities, this thesis articulates that care is also particular and "bespoke" – and the necessary outcome and ethic for a parallel PFM approach that is maximalist, abundant, adaptive, reparative, differentiated and underscores an embodied human relationality – something which AI proliferation cannot replace.

Through this thesis I hone in on how focusing on profound disabilities complicates assumptions undergirding traditional rights-based frameworks and participatory processes, presupposed on the belief of the autonomous individual and capacity for self-advocacy; and in the process demonstrate the necessity of rights-based endeavors to be a means, but not necessarily the outcome in itself. The outcome, it is evident, very much needs to hold on to the ideals and imaginations of justice. By clarifying the PFM agenda, this thesis aims to inject some strategic dimensionality and offer an intersectional roadmap to otherwise nebulous planning frameworks catered for social justice, such as the right to the city and antisubordination planning. It does so by beginning to conceptualize the assemblage of a disability justice-centric PFM framework and process that is tuned to the absolute margins; the compounded misfit and vulnerability that is silhouetted when a disabled environment meets a disabled body.

Figure 10: This bench, displayed as part of Constitution Court's art collection, was made by artist Azwifarwi Ragimana for Justice Zak Yacoob, a blind man who served on the Constitutional bench from 1998-2013. The artist carved textured hands to symbolize the importance of a sense of touch. Yacoob used the table to read braille documents in the Court's garden.

Bibliography

"80 Men in South African Court on Charges of Raping 8 Women." August 1, 2022. https://www.9news.com.au/world/south-african-rape-court-80-men-charges-of-raping-8-women/a1dad92b-20b1-422b-8599-b0fa86e13ebb.

Al Jazeera. 2022. "South Africa Most Unequal Country in the World: Report," March 10, 2022. https://www.aljazeera.com/news/2022/3/10/south-africa-most-unequal-country-in-the-world-report.

Barad, Karen. 2007. *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning*. Durham, NC: Duke University Press.

Baynton, Douglas C. 2001. "Disability and the Justification of Inequality in American History." In *The New Disability History: American Perspectives*, edited by Paul K. Longmore and Lauri Umansky, 33–55. NYU Press.

Binet, Andrew. 2015. "The Practice and Politics of Care : Social Service Organizations, Community Resilience and the Redevelopment of Regent Park." Thesis, Massachusetts Institute of Technology. https://dspace.mit.edu/handle/1721.1/98925.

Binet, Andrew, Rebecca Houston-Read, Vedette Gavin, Carl Baty, Dina Abreu, Josée Genty, Andrea Tulloch, Azan Reid, and Mariana Arcaya. 2023. "The Urban Infrastructure of Care." *Journal of the American Planning Association* 89 (3): 282–94. https://doi.org/10.1080/01944363.2022.2099955.

Bogen, Mitch. 2016. "2016 Ikeda Forum: Democracy, Inclusion, Community | Ikeda Center for Peace, Learning, and Dialogue." *Ikedacenter.Org*, October 27, 2016. https://www.ikedacenter.org/updates/2016-ikeda-forum-democracy-inclusion-community.

Bonner, P. L., and Lauren Segal. 1998. *Soweto: A History*. Maskew Miller Longman.

Buck, Nicholas. 2020. "COVID-19 and the Limits of Utilitarianism." *The University of Chicago Divinity School* (blog). June 11, 2020. Accessed June 13, 2023.https://divinity.uchicago.edu/sightings/articles/covid-19-and-limits-utilitarianism.

Cabe, Musawenkosi, Photographer: Ihsaan Haffejee, and News. 2018. "City Begrudgingly Lights up Slovo Park." New Frame. August 28, 2018. https://www.newframe.com/city-begrudgingly-lights-slovo-park/.

Capri, Charlotte, Lameze Abrahams, Judith McKenzie, Ockert Coetzee, Siyabulela Mkabile, Manuel Saptouw, Andrew Hooper, Peter Smith, Colleen Adnams, and Leslie Swartz. 2018. "Intellectual Disability Rights and Inclusive Citizenship in South Africa: What

Can a Scoping Review Tell Us?" *African Journal of Disability* 7 (0): 17. https://ajod.org/index.php/ajod/article/view/396.

Cooper, Davina. 2007. "`Well, You Go There to Get off': Visiting Feminist Care Ethics through a Women's Bathhouse." *Feminist Theory* 8 (3): 243–62. https://doi.org/10.1177/1464700107082364.

Crawford, Akex. 2013. "South Africa: Women Drinking To Harm Babies." Sky News. January 5, 2013. https://news.sky.com/story/south-africa-women-drinking-to-harm-babies-10458834.

Cunliffe-Jones, Peter. 2013. "No Evidence for Sky Claim Women Drink to Harm Babies and Collect Benefit." Africa Check. August 8, 2013. http://africacheck.org/fact-checks/reports/no-evidence-sky-claim-women-drink-harm-babies-and-collect-benefit.

Davis, Lennard J. 2018. "Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century." In *Beyond Bioethics*, 63–72. University of California Press. https://doi.org/10.1525/9780520961944-010.

De Jong, Michelle, Asha George, and Tanya Jacobs. 2021. "A Scoping Review of the Determinants of Foetal Alcohol Spectrum Disorder in South Africa: An Intersectional Perspective." *Health Policy and Planning* 36 (9): 1459–69. https://doi.org/10.1093/heapol/czab101.

Ebrahim, Tiffany. 2020. "OP-ED: Build It and They Will Come: Lessons from the Slovo Park Informal Settlement." Daily Maverick. July 29, 2020. https://www.dailymaverick.co.za/article/2020-07-29-build-it-and-they-will-come-lessons-from-the-slovo-park-informal-settlement/.

Fainstein, Susan S. 2014. "The Just City." *International Journal of Urban Sciences*, March. https://www.tandfonline.com/doi/abs/10.1080/12265934.2013.834643.

Fineman, Martha. 2004. *The Autonomy Myth: A Theory of Dependency*. New Press.

Flyvbjerg, Bent. 1998. *Rationality and Power: Democracy in Practice*. *Social Forces*. Vol. 78. https://doi.org/10.2307/3005579.

Fujikane, Candace. 2021. *Mapping Abundance for a Planetary Future: Kanaka Maoli and Critical Settler Cartographies in Hawai'i*. Durham, NC: Duke University Press.

Full Fact Team. "Are South African Women Drinking to Disable Their Unborn Children?" Full Fact. January 9, 2013. https://fullfact.org/news/are-south-african-women-drinking-disable-their-unborn-children/.

Garland-Thomson, Rosemarie. 2011. "Misfits: A Feminist Materialist Disability Concept." *Hypatia* 26 (3): 591–609. https://www.jstor.org/stable/23016570.

Goodley, Dan, Rebecca Lawthom, Kirsty Liddiard, and Katherine Runswick-Cole. 2022. "Affect, Dis/Ability and the Pandemic." *Sociology of Health & Illness*, June. https://doi.org/10.1111/1467-9566.13483.

Grech, Shaun, and Karen Soldatic, eds. 2016. *Disability in the Global South: The Critical Handbook*. Cham: Springer International Publishing. https://doi.org/10.1007/978-3-319-42488-0.

Hall, Suzanne, Henrietta Nyamnjoh, and Liza Rose Cirolia. 2022. "Apportioned City: Gendered Delineations of Asylum, Work and Violence in Cape Town." *Environment and Planning D: Society and Space* 40 (1): 3–20. https://doi.org/10.1177/02637758211048199.

Hamraie, Aimi. 2013. "Designing Collective Access: A Feminist Disability Theory of Universal Design." *Disability Studies Quarterly* 33 (4). https://doi.org/10.18061/dsq.v33i4.3871.

———. 2021. "Crip Mobility Justice: Ableism and Active Transportation Debates." *IJURR*, Spotlight On The Disabling City, . https://www.ijurr.org/spotlight-on/disabling-city/crip-mobility-justice/.

Harvey, David. 2008. "The Right to the City." *New Left Review* II (53): 23–40. https://newleftreview.org/issues/ii53/articles/david-harvey-the-right-to-the-city.

———. 1985. "On Planning the Ideology of Planning." In *The Urbanization or Capital*, 165–84. Johns Hopkins University Press.

Haughton, Graham, and Iain White. 2019. *Why Plan?: Theory for Practitioners*. Lund Humphries.

Hendren, Sara. 2020. *What Can a Body Do?: How We Meet the Built World*. Penguin Publishing Group.

———. 2023. "The Tent and the Estuary." May 30, 2023. https://sarahendren.com/2023/05/30/the-tent-and-the-estuary/.

Hirschman, Albert O. 1970. "The Search for Paradigms as a Hindrance to Understanding." *World Politics* 22 (3): 329–43. https://doi.org/10.2307/2009600.

Hodal, Kate. 2018. "Township Trauma: The Terrible Cost of Drinking during Pregnancy." *The Guardian*, May 27, 2018, sec. Global development. https://www.theguardian.com/global-development/2018/may/27/mothers-children-foetal-alcohol-syndrome-south-africa.

Honwana. 2013. "Youth, Waithood, and Protest Movements in Africa - GSDRC." International African Institute. https://gsdrc.org/document-library/youth-waithood-and-protest-movements-in-africa/.

Huchzermeyer, Marie. 2019. “Informal Settlements and Shantytowns as Differential Space.” In *The Routledge Handbook of Henri Lefebvre, The City and Urban Society*, edited by Michael E Leary-Owhin and John P. McCarthy. Routledge.

———. 2021. “A Critical Lefebvrian Perspective on Planning in Relation to Informal Settlements in South Africa.” *Town and Regional Planning* 79: 44–54. https://doi.org/10.18820/2415-0495/trp79i1.6.

Jürgens, Ulrich, Ronnie Donaldson, Stephen Rule, and Jürgen Bähr. 2013. “Townships in South African Cities – Literature Review and Research Perspectives.” *Habitat International* 39 (July): 256–60. https://doi.org/10.1016/j.habitatint.2012.10.011.

Kafer, Alison. 2013. *Feminist, Queer, Crip*. Indiana University Press.

Kudva, Neema. 2009. “The Everyday and the Episodic: The Spatial and Political Impacts of Urban Informality.” *Environment and Planning A: Economy and Space* 41 (7): 1614–28. https://doi.org/10.1068/a41101.

Lefebvre, Henri. 1996. *Writings on Cities*. Wiley.

McDowell, Ceasar. 2015. “Democracy from the Margins.” Presented at the TEDxIndianaUniversity, Indiana University, December 26. https://www.youtube.com/watch?v=irkqd0q9a9k.

———. 2018. “Diversity Is Not Enough.” *MIT Faculty Newsletter* (blog). June 2018. https://web.mit.edu/fnl/volume/305/mcdowell.html.

Meekosha, Helen, and Leanne Dowse. 1997. “Enabling Citizenship: Gender, Disability and Citizenship in Australia.” *Feminist Review* 57 (1): 49. https://www.academia.edu/1079757/Enabling_Citizenship_Gender_disability_and_citizenship_in_Australia.

Meekosha, Helen, and Karen Soldatic. 2011. “Human Rights and the Global South: The Case of Disability.” *Third World Quarterly* 32 (8): 1383–98. https://www.jstor.org/stable/41300291.

Miles. 2010. “The Chuas of Shah Daulah at Gujrat, Pakistan: Evidence, Historical Background and Development, with Bibliography 1839-2009.” 2010.

Miraftab, Faranak. 2009. “Insurgent Planning: Situating Radical Planning in the Global South.” *Planning Theory* 8 (1): 32–50. https://www.jstor.org/stable/26165884.

Mitchell, David T., and Sharon L. Snyder. 2000. *Narrative Prosthesis: Disability and the Dependencies of Discourse*. University of Michigan Press. https://doi.org/10.3998/mpub.11523.

Natarajan, Lucy. 2017. “Socio-Spatial Learning: A Case Study of Community Knowledge in Participatory Spatial Planning.” *Progress in Planning*, Socio-spatial learning: A case study of community knowledge in participatory spatial planning, 111 (January): 1–23. https://doi.org/10.1016/j.progress.2015.06.002.

Nation, The Red. 2021. *The Red Deal: Indigenous Action to Save Our Earth*. Common Notions.

Neilson, David. 2015. “Class, Precarity, and Anxiety under Neoliberal Global Capitalism: From Denial to Resistance.” *Theory & Psychology*, April. https://doi.org/10.1177/0959354315580607.

“Pandemic Urbanism: Praxis in the Time of Covid-19.” 2020. https://bit.ly/pandemicurbanism.

Pascoe, Jordan, and Mitch Stripling. 2020. “Surging Solidarity: Reorienting Ethics for Pandemics.” *Kennedy Institute of Ethics Journal* 30 (3): 419–44. https://doi.org/10.1353/ken.2020.0022.

Peabody-Smith, Ally. 2022. “How Should (and Shouldn’t) We Think About Profound Intellectual Disability?” *The Journal of Philosophy of Disability* 2 (November): 112–29. https://doi.org/10.5840/jpd2022102517.

Piepmeier, Alison. 2013. “The Inadequacy of ‘Choice’: Disability and What’s Wrong with Feminist Framings of Reproduction.” *Feminist Studies* 39 (1): 159–86. https://doi.org/10.1353/fem.2013.0004.

Piepzna-Samarasinh, Leah Laksmi. 2022. *The Future Is Disabled: Prophecies, Love Notes and Mourning Songs*. https://arsenalpulp.com/Books/T/The-Future-Is-Disabled.

Prigarina, Natalia. 2012. “Sarmad: Life and Death of a Sufi.” In *Ishraq Islamic Philosophy Yearbook*, edited by Yanis Eshots, 319. Moscow: VostochnayaLiterature Publishers. chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://iphras.ru/uplfile/smirnov/ishraq/3/24_prig.pdf.

Puar, Jasbir K. 2017. *The Right to Maim: Debility, Capacity, Disability*. ANIMA: Critical Race Studies Otherwise. Durham, NC: Duke University Press.

Purcell, Mark. 2014. “Possible Worlds: Henri Lefebvre and the Right to the City.” *Journal of Urban Affairs* 36 (1): 141–54. https://doi.org/10.1111/juaf.12034.

Rigot, Afsaneh. 2022. “Design From the Margins.” Belfer Center for Science and International Affairs Harvard Kennedy School. https://www.belfercenter.org/publication/design-margins.

Roy, Ananya. 2005. “Urban Informality: Toward an Epistemology of Planning.” *Journal of the American Planning Association* 71 (2): 147–58. https://doi.org/10.1080/01944360508976689.

Royston, Nomzamo Zondo & Lauren. 2016. “Upgrading Informal Settlements: The Importance of the Slovo Park Judgment.” Daily Maverick. April 10, 2016. https://www.dailymaverick.co.za/article/2016-04-11-upgrading-informal-settlements-the-importance-of-the-slovo-park-judgment/.

Samuels, Ellen. 2017. “Six Ways of Looking at Crip Time.” *Disability Studies Quarterly* 37 (3). https://doi.org/10.18061/dsq.v37i3.5824.

Sandoval, Vicente, and Juan Pablo Sarmiento. 2020. “A Neglected Issue: Informal Settlements, Urban Development, and Disaster Risk Reduction in Latin America and the Caribbean.” *Disaster Prevention and Management: An International Journal* 29 (5): 731–45. https://doi.org/10.1108/DPM-04-2020-0115.

Savulescu, Julian, Ingmar Persson, and Dominic Wilkinson. 2020. “Utilitarianism and the Pandemic.” *Bioethics* 34 (6): 620–32. https://doi.org/10.1111/bioe.12771.

Shelton, Sam Z. 2021. “Bringing the Pandemic Home: The Shifting Realities of Intimate Violence for Disabled People in the Time of COVID-19.” *Disability Studies Quarterly* 41 (3). https://doi.org/10.18061/dsq.v41i3.8392.

Stafford, Lisa, Leonor Vanik, and Lisa Bates. 2022. “Disability Justice and Urban Planning.” *Planning Theory and Practice* 23 (1). https://doi.org/10.1080/14649357.2022.2035545.

Steil, Justin. 2022. “Antisubordination Planning.” *Journal of Planning Education and Research* 42 (1): 9–18. https://doi.org/10.1177/0739456X18815739.

Steil, Justin, and Delgado. 2019. “Limits of Diversity: Jane Jacobs, the Just City, and Anti-Subordination.” *Cities* 91 (August): 39–48. https://doi.org/10.1016/j.cities.2018.06.017.

Terashima, Mikiko, and Kate Clark. 2021. “The Precarious Absence of Disability Perspectives in Planning Research.” *Urban Planning* 6 (1): 120–32. https://doi.org/10.17645/up.v6i1.3612.

Thrift, Nigel. 2004. “Intensities of Feeling: Towards a Spatial Politics of Affect.” *Geografiska Annaler. Series B, Human Geography* 86 (1): 57–78. https://www.jstor.org/stable/3554460.

Tuck, Eve. 2009. “Suspending Damage: A Letter to Communities.” *Harvard Educational Review* 79 (3): 409–27. https://doi.org/10.17763/haer.79.3.n0016675661t3n15.

Umemoto, Kare. 2001. “Walking in Another’s Shoes: Epistemological Challenges in Participatory Planning.” *Journal of Planning Education and Research* 21 (1): 17–31. https://doi.org/10.1177/0739456X0102100102.

Uniacke, Suzanne, and H. J. McCloskey. 1992. "Peter Singer and Non-Voluntary 'Euthanasia': Tripping down the Slippery Slope." *Journal of Applied Philosophy* 9 (2): 203–19. https://www.jstor.org/stable/24353688.

Weibgen, Adrien A. 2015. "The Right To Be Rescued: Disability Justice in an Age of Disaster." *THE YALE LAW JOURNAL*.

Welton, Michael. 2020. "Autobiographical Roots of Habermas' Thought." CounterPunch.Org. January 28, 2020. https://www.counterpunch.org/2020/01/28/autobiographical-roots-of-habermas-thought/