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Pressure Points In The System: Ontological perspectives on the labour of changemaking

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In this paper, I present a selection of ontological perspectives of marginalised people in relation to their experiences of labour entangled with and within the paradigm of changemaking.

Building upon the seminal work of systemic designer Donella Meadows on "leverage points in the system" (Meadows, 1999). Meadows' leverage points in the system are pivotal junctures where small changes can lead to profound shifts in complex systems. However, my focus diverges towards the ontological realities of those who exist and labour at pressure points of change that exist at many places throughout systems and societal structures. It focuses on those who are left with the burden of enacting the change designed by others in more privileged positions. This paper aims to be a snapshot of the *pressure points* in the system. Latina feminista scholars refer to this style of academic writing as *testimonios* (Morales et al., 2020). These *Testimonios* serve to deepen understanding of the radical systemic issues that can occur when mechanistic interventions focus on change rather than those tasked with the labour of enacting that change.

Changemaking is often associated with grand ambition, protest, and political reform. However, for marginalised people, it is a constant process of self-advocacy, retrofitting surroundings, relationships, and themselves to *simply* sustain their existence in a world designed for other people's comfort (Spencer, 2022a).

It is important to note, so as not to permeate reductive or abstractive narratives about marginalised people, that these stories of oppression and difficulties exist within the colourful and diverse lives of marginalised people. This is not a depiction of the life of persons living on the margins of a dominant culture aimed to promote pity or saviourism. These testimonios are “a crucial means of bearing witness and inscribing into history those lived realities that would otherwise succumb to the alchemy of erasure” (Cepeda, 2021).

When discussing systemic change, Meadows refers to the importance of not using the “same old faucets, plumbed into the same old systems” (Meadows, 1999, p. 5) These are the stories of those faucets.

KEYWORDS: disability justice, mobility justice, design justice, ontological design, leverage points.

RSD TOPICS: Cases & Practice, Methods & Methodology, Society & Culture

Introduction

I am a disabled feminist academic, and I centre my work on the complex and uncertain realities of disabled people and their lives. My work also aligns with the disability justice (Piepzna-Samarasinha, 2018) principles that recognise that “we would not think of disability as separate from class, age, race, queerness, family, children, violence, but we would understand it as intimately connected” (Mingus, 2010).

This paper examines the systemic entanglement of changemaking and (im)mobilities within the lived experiences of marginalised people and their communities. Murray et al. describe (im)mobilities as: “not only the absence of movement, but the constraining of movement in particular ways- both corporeally and emotionally set within a landscape of culture, legal, gender, national, political and personal.” (Murray et al 2021).

In my previous (RSD11) paper, Rethinking Participatory Design Research Methodologies (Spencer, 2022b), I presented ideas on a developing theory that centres minimising the burden of change on the shoulders of the oppressed as a design process. The paper

focused on how this centring can be a positive catalyst to creativity rather than a blockade to working practice. In that paper, I discussed the concept of the labour of participation within changemaking (Spencer, 2022a) and its disproportionate nature for marginalised people. Changemaking is often associated with grand ambition, protest, and political reform. However, for marginalised people, it is a constant process of self-advocacy, retrofitting their surroundings, relationships, and even themselves to *simply* sustain their existence in a world designed for other people's comfort.

In this paper, I have chosen to focus on sharing the lived experiences of those who labour at the levers of change and how that pressure manifests as (im)mobilities (Sheller, 2018). These stories illustrate how systemic failures manifest as points of pressure for those who are often least able to bear the labour of enacting that change without significant negative impacts on their lives. Devoting vital time and energy to basic rights leaves less room for other endeavours that could be more focused on progression and forward movement, both physically and socioeconomically. This is particularly poignant for members of the disabled community who often experience energy shortages and physical (im)mobilities as a direct result of how their bodyminds exist in a world designed for abled people. The implications of these (im)mobilities can lead to anything from unemployment, lack of education, isolation to actual physical pain and illness.

I have chosen to explore these ontologies through artworks and poetry as well as academic written texts, as I believe it is important to create space within academia for non-academic voices to be heard.

This paper also explores the relationship between oppression and these hidden systemic labours. Renowned black feminist scholar Collins characterizes Eurocentric masculinist society as functioning within a *matrix of domination*. Central to this matrix is a hierarchical structure that perpetuates oppression onto marginalised individuals through intersecting axes of otherness (Collins, 1990). Consequently, the experience of oppression and its effects vary for each individual. In this paper, I present these forms of oppression as labour, a tax on existing before we have even begun the work of life. Building upon Collins' framework, I discuss how we can design better systems by acknowledging and incorporating these lived experiences. Design justice and disability justice principles further reinforce this understanding, recognising that any given design

advantages some people and disadvantages others according to intersecting social structures such as race, disability, and gender (Costanza-Chock, 2020).

Designers are a dangerous breed (Escobar, 2011) that hold the power to choose who will experience that disadvantage and who will not. Those who strive to eliminate complexity and drive out labour only serve to push that labour down the system to those who are least likely to have a direct impact on the designer's own viewpoint of the world. The work often then falls on marginalised people who are already existing at a time and energy deficit due to the taxing nature of oppression on their day to day lives. Change is movement, and movement requires energy. Those are inarguable cosmic facts. Therefore, those with less energy to spare are less able to mobilise.

As designers, we must focus on understanding exactly who and where that energy will come from. Ontological designing (Willis, 2006) from stories of people's experiences outside of our traditional research groups and controlled academic environments can help us to begin to decode that flow of labour. From there, we can begin to unlearn what we think we know and embrace the radical uncertainties (Sweeting et al., 2021) and pluralities (Escobar, 2011) that exist beyond our own predetermined knowledge of the world around us. We can begin to design from a place that truly challenges the official designations of power (Von Busch, 2022).

The un-erasable nature of burden

Before I go on to discuss how the day-to-day life of marginalised people is intrinsically entangled with changemaking, it is important to address these intrinsic labours are not unchangeable. These labours have been designed into systems produced by people from dominant cultures who may be unaware of their existence. The issue is that designing systems that streamline and uncomplicate life only leads to pushing problems further down the line. The labour of change cannot be erased, only shifted over.

Bailey writes:

The academy was built on the labour of women and other marginalised people who did the work of life so that these philosophers could enjoy a life of the mind. (Bailey, 2021, p. 289)



Figure 5. The work of artist Maravilla: Seven Ancestral Stomachs. Crip Time Exhibition 2022, Frankfurt MMK. www.mmk.art/en/whats-on/crip-time/

In this statement, Bailey is talking about the housekeepers and housewives of philosophers, but it could be just as easily about the human subjects that were studied themselves. Sheller describes a similar cultural phenomenon that exists at an intersectional level within women's historical unburdening's. "The liberation of white women to enjoy freedom of movement may in fact be predicated on the subordination of women of colour who became the colonized women of burden" (Sheller, 2018, p. 50). This is an important aspect of understanding both the ontological implications of existing in the change and the un-erasable nature of burden. One person's freedom will likely mean another person's unfreedom (Le Guin, 2001).

Artist Guadalupe Maravilla's work, *Seven Ancestral Stomachs* (Figure 5), describe how these injustices traumas pass down through generations. Maravilla's work is based on the knowledge of the Indigenous People of the Americas that each person must consider the impacts of their decisions on the seven generations after themselves (Loew 2014). In this artwork he reflects on the impact the last seven generations have had on him. He talks about an extensive healing process after surviving a battle with cancer

that started in his gut, as well as that of his family. Maravilla's work delves into the interconnection between personal struggles and the physical repercussions of being an undocumented immigrant for over 18 years of his life. He is particularly focused on how this has affected his gut health.

He discusses the legacy of poverty and malnutrition endured by his Salvadoran ancestors and examines how this collective genetic trauma has manifested in his and his families' bodies (ArtRabbit 2021).

This poignant work further illustrates the un-erasable nature of the burden of change. Not only can it exist in the time that it is happening, but it can also continue to permeate through generations building up and transcribing itself on the body and mind in an endless cycle of illness and health (Günzel et al., 2022) from generational trauma that perpetuates generational (im)mobilities.

The invisible work

I thought to begin this journey at the start, where all human things begin.

At the birth of her daughter Beth, illustrator and author Henny Beaumont writes, "I found it almost impossible to love her, because of her disability" (Beaumont, 2016). I chose to discuss this statement not as a judgement on this mother but as an example of how systemic sexist and ableist cultural narratives entangle at the deepest point of our humanity. Even the love of a mother is not guaranteed.

Cultural standards such as these violate the sense of self of women and individuals who give birth, as they feel judged based on the 'quality' of the children they produce. Right from the start, this mother and child are at the pressure point of this systemic entanglement. It is their job to learn how to love or be loved.

This feeling of being difficult to love is a thread that connects through many marginalised people's lives (Ertel, 2023). It could be argued that writing a book around this issue is problematic and appropriative of the child's struggles, highlighting the abled persons lived experience over the disabled persons and reinforcing negative cultural assumptions about *disabled people*. Others might say that we need to allow space for such discussions, so that parents and families can be supported with overcoming or living with these systemic pressure sores. I am not able to, nor do I

profess any desire to choose a side in this complex emotional issue. To intellectualise it completely would be to flatten and dehumanise it. However, I would be remiss not to recognise this tension within the discourse. My position is that these realities must be discussed in their messiness. Too often, these experiences are disputed or disbelieved by institutions of power (Sheller, 2018) due to the need for homogeneity in traditional systemic thinking. I choose to complicate, problematise and allow space for opposition and agonism (DiSalvo, 2015).

When I say tell the truth I mean complicate. (Hershey, 2010)

The next step on our ontological road trip reflects on the work of Mia Mingus, co-founder of the Disability Justice movement, and her experience of attending the Allied Media Conference in 2010. This was the first year that Disability Justice was to have a space in this social justice conference. It became clear that getting there and existing in that space of change would be a monumental task for those with disabilities, chronic health conditions and neurodivergent minds. In Mingus' reflection, she discusses the burden of inaccessibility as feeling "the weight of what inaccessibility meant to us" (Mingus, 2010). Mia, Leah Lakshmi Piepzna-Samarasinha and Stacy Milbern began working on a project called Creating Collective Access, a project that encompassed the complexities of disability beyond the simple logistical aspects of moving people from one place to another. It was the lived experiences of being disabled and living within crip culture with disabled friends and family that enabled these *3 crip femmes* (Mingus, 2010) to actualise such a complex and difficult undertaking. Even though they knew that it would take a toll on their bodyminds and be a huge amount of work, there was no other option. In this story we again see a tax on the people who would arguably be the most negatively impacted by bearing the burden of the workload. This workload of supporting accessibility issues beyond wheelchair ramps at the venue, was either invisible to the organizers or deemed unachievable. However, for these 3 crip femme they were impossible to ignore. Mingus highlights the pervasive oversight of lesser-known accessibility requirements, even within events that are dedicated to fostering change and promoting social justice.

Knowing we had to do it for ourselves because it is so rare for movement spaces to consider accessibility beyond logistics. (Mingus, 2010)

Mingus discusses how these complexities surpassed the organisational capabilities of the event designers and yet these 3 crip femmes with limited energies and unreliable bodies, managed to organise and support their disabled friends and colleagues to attend the event. Given who they are and what they know, they felt uniquely positioned to contribute to the fight in this way (Padamsee, 2019). The nature of their existence was intrinsically entangled in the reality that they would have to be the ones at the pressure point of this change because nobody else was able or willing to do it. At what cost though? How much of their lives did they have to give up doing this work? And what long term impact does this type of labour have on their lives. It seems that those impacts were not part of Mingus' recounting of the event. The absence of such an account does not mean, however that it did not occur. It seems likely that it was simply not included as part of the retelling.

This type of community labour is recognisable as a theme in marginalised communities of care (Padamsee, 2019). Leah Lakshmi Piepzna-Samarasinha describes *care webs* (Piepzna-Samarasinha, 2018) as another phenomenon within disabled communities of care. Care webs consist of groups of disabled people looking after each other, or what happens when "sick and disabled people are the only ones who do not forget about each other, but we are all extremely, extremely tired." (Piepzna-Samarasinha, 2018, p. 35)

Once again, we see systemic pressures manifesting as (im)mobilities entangled within the lives of marginalised people. Within care webs, the labour of these systemic pressure points is not lobbying governments or designing new systems, but instead making sure that your friend has taken their medication or is doing ok in a lockdown. The change occurs from many small acts of care by already exhausted people.

We who drive across town to deliver saltines. (Clare, 2021, p. 255)

Neoliberal narratives around the uselessness of tired, disabled bodies that spend too much time in bed (Piepzna-Samarasinha, 2018) permeate through our culture whilst simultaneously playing a huge factor in that tiredness.

Having to support and care for fellow marginalised people at the same time as fighting through our own battles to simply get our basic needs met creates a cycle of *invisible*



Figure 1: The work of artist Emily Barker: *Epistemologies*. Crip Time Exhibition 2022, Frankfurt MMK. <https://www.mmk.art/en/whats-on/crip-time/>

work that is neither celebrated nor acknowledged in ableist systemic structures of capitalist neoliberalism.

Artist Emily Barker's "epistemologies" (Figure 1) work describes and emotes this invisible work. The sculptural piece, a set of folders containing concrete slabs, illustrates the never-ending invisible workload of managing the paperwork of chronic illness. She refers to the violence of administrative language that degrades and dehumanises her (Günzel et al., 2022). The invisible work of making sure you remain healthy is a struggle that exists for every disabled person and/or their carer. This outpouring of energy and time, leaves disabled people and/or their carers with little time to do anything else. This piece resonates strongly with my own experiences of disability. These blocks of concrete represent the weight of this burden, it weighs us down and holds us in place. We cannot move forward in our lives as we are anchored into place by our never-ending battle to be heard and to coordinate the care of our bodies within a system that is riddled with sexism and ablism. This burden limits our ability to work, have relationships and even enjoy rest. The impact of which is therefore felt in every aspect

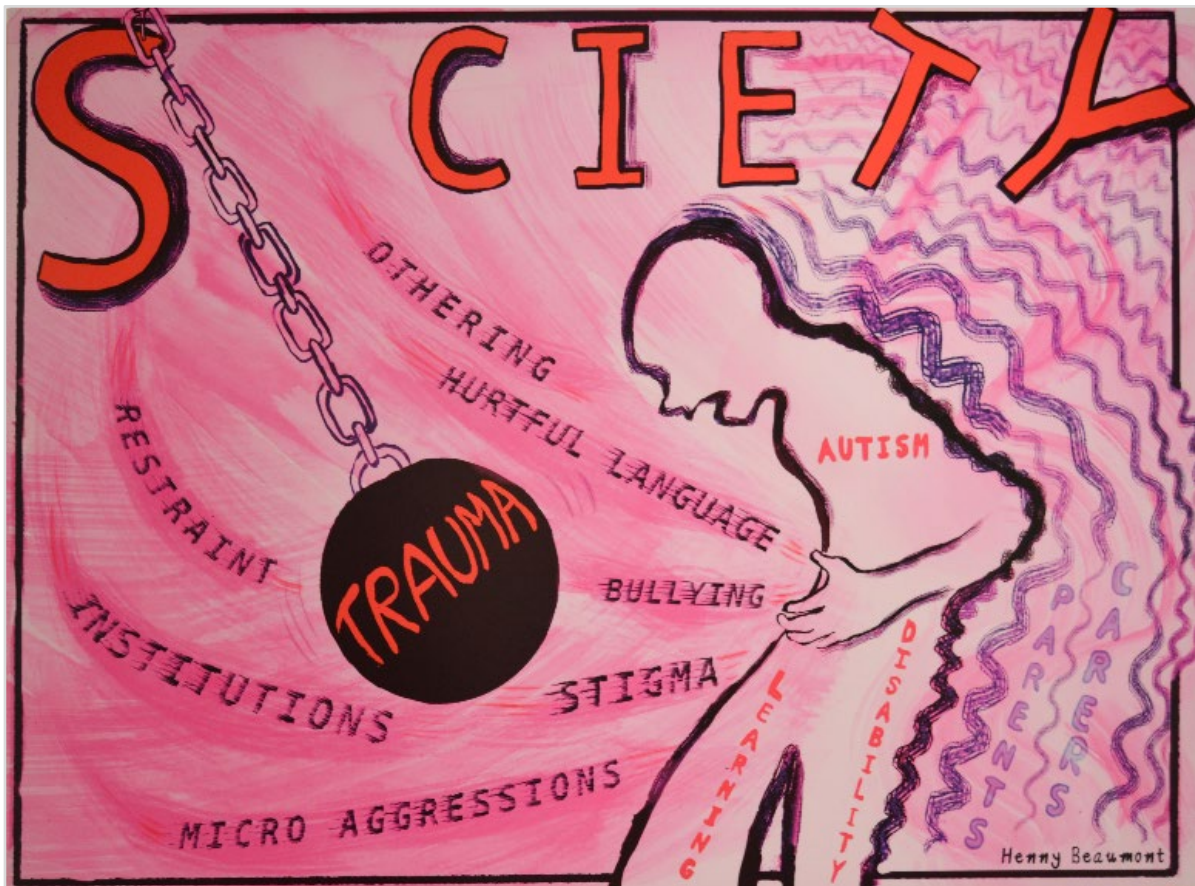


Figure 2: Illustration "society" by Henry Beaumont at the Invisible People exhibition. Worthing Museum. Photo by Author. 2022

of our mobilities, from the macro socioeconomic to the most intimate of micro (im)mobilities of being able to move out of a mental space of stress and worry, into a space of inner peace and calm.

Henry Beaumont's "invisible people" (Beaumont, 2022) exhibition at Worthing Museum explores the insidious nature of this '*invisible work*' brought about by systemic injustices, depicting the subsequent ways in which it impacts (im)mobilities.

Her illustrations relate to the lived experiences and challenges of disabled people and their carers living in a world designed for able-bodied and neurotypical people.

In her illustration named "society" (Figure 2), a black wrecking ball with the word trauma written on it is striking a human form. This visual representation of trauma illustrates how commonplace societal injustices significantly impact on a person's psychological and physical health. The illustration is accompanied by a text where trauma is described



Figure 3. Illustration "Inclusion" by Henny Beaumont at the Invisible People exhibition. Worthing Museum. Photo by Author. 2022

as "a series of wounds. it is experienced as a threat to our life or mind. it goes through you" (Beaumont, 2022). Collins' Matrix of domination emphasizes the entangled nature of various forms of oppression and othering that individuals face. Beaumont's visual metaphor in the image illustrates how that experience can manifest as trauma and exclusion. The image highlights the pain and trauma caused by oppression, underscoring the profound impact that institutionalised discrimination and cultural norms can have. This trauma not only isolates and violates individuals but also restricts their mobilities within society.

By tying together Collins' conceptual framework with Beaumont's visual representation, we see a powerful depiction of how systemic oppression operates and its consequences on individual experiences. It emphasises the significance of the ontological research process within systems design, without which we miss these systemic pressure sores that act so vividly on some of the most vulnerable members of society.

Beaumont's illustration on inclusion (Figure 3) expresses this in the form of a child and parent feeling othered in the playground at drop-off time.

This illustration represents the failure to accommodate a child's needs, who might need a longer period of time to acclimatise to a new school or even a new school day, leaving the parent and child to manage these issues without adequate support, resulting in parents feeling like failures and children being labelled as '*badly behaved*'. These labels and judgements lead to a deeper undercurrent of isolation through micro-(im)mobilities created through exclusionist cultural conventions. Once again, the labour of change to be accepted falls on the shoulders of those who are in crisis. By prioritising the needs of the larger group of children, you are deprioritising the needs of the individual's physical and emotional safety. (Beaumont, 2022). This is an example of how systems designed for homogeneity over plurality can embed pressure points at the very worst places. Again, our most vulnerable members of society are expected to change themselves to fit into a rigid structure that is designed to support individuals from the dominant cultural group, in this case neuro-typical children. Escobar describes a pluriversal approach to design that can engage with the diverse spectrum of possibilities that humans present (Escobar 2011). Adopting a pluralistic approach in designing systems particularly when those systems are for humans, may give us the tools to be able to disperse some of that load more evenly.

This type of trauma exists within all marginalised people in one way or another. It even exists in those who are adequately able to advocate for themselves, collate/cope with piles of correspondence, or magnificent feats of crup care organisations. But what of those who are unable to do that? How does existing within the paradigm of changemaking look when it goes wrong in the eyes of society? What of those who fall through the cracks—who don't look sick or don't even know they have issues? What if your idea of changemaking is to have nicer things, pay the rent or even have fun, yet you were not supported by society to achieve those goals legally or in a way that works for you?

Beaumont's illustration of the legal system (Figure 4) depicts the barriers and struggles that many people face within it. For certain people, the solution to having more money or paying rent is to simply get a better job or work harder, for many that is littered with barriers and, in some cases, impossibilities.



Figure 4: Illustration "Legal Systems" by Henny Beaumont at the Invisible People exhibition. Worthing Museum. Photo by Author. 2022

A study showed that 70% of the male UK prison population have speech and language issues. (Coles, Gillett et al. 2017, p.13) This telling statistic demonstrates how ableist systemic cultural narratives entangle with a person's ability to choose the 'right path' in life. Therefore, changemaking can become criminal.

The invisible work of being heard is crucially connected to this scenario of entanglement. Rather than creating systems of change that punish people in crisis, should we not be working on systems that develop our cultural ability to listen collectively?

Le Guin describes a character in one of her books who has speech and language issues: "Nobody had ever taught her to think consecutively. Nobody had ever listened to what she had said" (Le Guin, 2001, p. 46). In this, we can understand that in the place of changemaking and communication, the activity of listening is not a passive act. By

listening, hearing, and processing, we can create a dialogue that in itself helps those who struggle to be heard, to be heard. Inherently producing systems that share the burden of this invisible work with the masses rather than the few.

Through all four of these artworks, we can see threads of connection that weave in and out of these stories. Being dehumanised and isolated plays a distinct part in Emily Barker's epistemologies as well as Henny Beaumont's trauma and inclusion illustrations. They illustrate the powerful barriers existing at the pressure points of systemic change. These artworks highlight the energy required to overcome those barriers and how these intersecting impacts affect an individual's mobilities. In the final illustration we see how that dehumanisation, isolation and therefore (im)mobilities manifest in a broader socio-systemic way: as criminal incarceration.

Conclusion

In conclusion, this paper delves into lesser-known interplays between systemic change and the lived experiences of marginalised individuals. It highlights the burden placed on those at the pressure points of systemic changemaking, who often find themselves navigating complex entanglements of ableism, sexism, and other intersecting oppressions.

By centring the voices and experiences of marginalized communities through ontological narratives, this paper highlights the importance of recognizing and addressing the systemic inequalities inherent in design and therefore societal systems. I argue that an Ontological approach to systemic design can enable designers to contextualise radical uncertainties and experiences of marginalised people living within the matrix of domination.

Ultimately, this paper calls for a collective reimagining of systems and structures, one that acknowledges the inherent complexities and inequalities ingrained within them. By listening, learning, and embracing pluralities, we can begin to unravel the systemic entanglements that perpetuate injustice and work towards a more equitable and inclusive society.

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