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Rethinking Participatory Design Research Methodologies

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Recentring changemaking research practices around minimising the placement of the burden of change on the shoulders of the oppressed

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This presentation is an exploration of changemaking design practices centred around the problematics of engagement through the lens of micro-(im)mobilities (Sheller, 2018, p2) that are reproduced in conventional participatory design and research methodologies. I have observed that traditional social design, co-design and focus group models of academic social research lean heavily on the labour of the oppressed for the gain of those in positions of power.

As a disabled woman with fluctuating health, mental and physical capacities, I must live in an extremely mindful way, measuring my energy levels and outputs like they are granules of gold dust. This gives me a lesser travelled path to and through my research and allows me a particular sensitivity to the burdens that I require of the people whom my work will benefit. With this in mind, as a consistent and defining characteristic of the experiences that myself and others are familiar with, I am working on a theoretical positioning around the principle of minimising the burden of change on the shoulders of the oppressed. I am working towards a balance between paternalistic speaking for others and the ideology of *Nothing About Us Without Us* (Germon, 2000). Having said that, I feel strongly that intersectional communities should be represented and be in

decision-making positions of power and that "in some instances speaking for others constitutes a violence" (Alcoff, 1991). However, I would argue that in many instances requiring others to speak for themselves to attain basic human rights is also a violence. Additionally, we are always speaking for others, even if we identify as a member of that community. Meadows discusses leverage points in the system (Meadows, 1999); my work aims to better understand and communicate the ontological perspectives of marginalised people within the paradigm of change-making and how they manifest as pressure points in the system. I aim to show that careful consideration of this standpoint can be a catalyst to creativity rather than a barrier to overcome.

This presentation includes examples of previous projects that have been designed from this standpoint. I will also be discussing and sharing personal reflections on my own experiences as a disabled woman in academia and the importance of Cripping my work. I will explore ways in which Crip culture can be assimilated into research practices to the benefit of the participants and the researcher.

KEYWORDS: Participatory design research, Crip Culture, Design Justice, Mobility Justice, Co-Design, Systemic injustice.

RSD TOPIC: Confronting Legacies of Oppression in Systemic Design, Methods & Methodology, Society & Culture.

Presentation summary

The overarching focus of my work as a researcher and sustainable designer is to work against isolation for people in marginalised communities. Isolation is the end point of all mobilities issues, and it is the ultimate outcome of (im)mobilities and drastically reduces the quality of life of the people who experience it. (im)mobilities manufacture isolation and therefore must be at the centre of all my enquiry. 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" (2021). As a disabled woman who identifies as a person from a marginalised community, I have personal experience of how those (im)mobilities manifest in day-to-day life to create barriers and increase isolation. The most tangible ones are micro(im)mobilities that are experienced at a "smaller bodily scale" (Sheller, 2018). This is the main focus of my exploration in understanding the problematics of changemaking design practices when bringing in participants from marginalised communities to inform them.

As a disabled woman with fluctuating health, mental and physical capacities, I practice "pacing my spoons" (Partlow, 2020) – a method of managing my energy levels and avoiding boom and bust behaviour that can lead to symptoms worsening. This method relies on extreme mindfulness and awareness of energy outputs and demands. The word fatigue is often interpreted as very tired, but for many people like me, it can lead to days or weeks of recovery, exacerbating pain levels and other unpleasant symptoms of chronic health issues combined with isolation. The lesser discussed element of participation is that a simple bus journey or an intense conversation might lead to these kinds of difficulties.

The labour of participation

In my presentation, I address these issues in what I call the "labour of participation" (Spencer, 2022), candidly discussing personal experiences of how this labour has affected me in my work and participation at events as a disabled academic and how they have inspired a working methodology that enables me to work carefully within my own fluctuating capacities. Additionally, this lesser travelled path, and through my research, allows me a particular sensitivity to the burdens that I require of the people whom my work will benefit. My presentation discusses ways in which this cripping of the work manifests as a positive catalyst to inspiration and how we can lessen the Labour of participation by infusing crip culture (Piepzna-Samarasinha, 2018) and "crip temporalities" (Samuels & Freeman, 2021) into our research practices.

Understanding the labour of participation to minimise the burden of change on the shoulders of the oppressed is part of this theory. However, it would be remiss of me not to acknowledge the tensions between "speaking for others" (Alcoff, 1991) and the

principles of "nothing about us without us" (Germon, 2000). This tension is ever-changing and subjective. To consider it in our work must mean that we embrace uncertainty and complexity in the systems that we are working with/in. However, systems crave structure, predictability and conformity, and any variations from this could equal losing control (Meadows, 1999). In this presentation, I discuss how this tension manifested systemically within my latest project and the academic research ethical framework. I will question how we can work ethically in "the framework of complexity theory?" (Bai, 2008) with people outside of our academic or design culture whilst enforcing a set of ethical boundaries that conflict with participants' own cultural ethics.

How can we embrace uncertainty and safety? I would argue that, as Tham writes, "humans exist only in a web of living co-vulnerabilities"(Tham, 2022) and therefore, to define an individual human as vulnerable simply because they may have a disability or other protected characteristic seems patronising at best. Understanding that vulnerability exists in us all, at one time or another, is the heart of this ethical standpoint. If our vulnerabilities are temporal, then our methodologies must be the route of how we explore the issue of vulnerability and how, when and most importantly, we should manifest it in our working practices. I'm proposing deep systemic reflection before embarking on research that involves marginalised communities discussing the stories and experiences of oppression with members of dominant cultures. As researchers, we are always dominant in our focus groups (Goodwill, van der Bijl-Brouwer & Bendor, 2021).

I present these ideas and possibilities alongside a series of design projects that have centred the theory of minimising the burden of change on the oppressed to create more just research practices rather than as a perceived barrier to the work. My projects cover ideas of how to use existing work to research more emotionally or physically draining topics rather than mining participants for their experiences and pain. Speculative systems designed for social change that put the burden of change on those in positions of power with my "Brighton's first wheelchair accessible pub crawl project" and how I used this principle to develop an allyship focus group infused with crip

culture and temporalties to create a more equitable and enjoyable way of exploring the issues surrounding oppression.

Meadows writes that the best place to enact systemic change is the leverage points in the system. My work focuses on the pressure points in the system, the people that labour at the lever of change and how that pressure manifests as (im)mobilities for marginalised people. What I am hoping to get from this work is a framework for a methodology that honours the ideals of "nothing about us without us" (Germon, 2000), which is all about getting marginalised people into decision-making positions of power, and not tokenistic gestures of participation (Piepzna-Samarasinha, 2018) that hold no real agency over the change but shoulders almost all the mental, temporal, emotional and physical burden of it. Diversity is the only sustainable option for systemic management, and we (marginalised people) can be leaders and/or the creatives doing the research that "functioning systems require the right skill mix" (Muggleton et al., 2022). As long as marginalised people are seen first and foremost as participants rather than researchers, then no amount of participatory research and design methods will lead to the inclusion it claims to produce. These internalised systems of oppression continue to be reproduced in our design practices (The Design Council, 2021). "Bottom-up methodology" (Hamraie, 2016) just keeps us at the bottom.

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