From the Desks of

Designers and Researchers bringing Design Justice Principles to Work
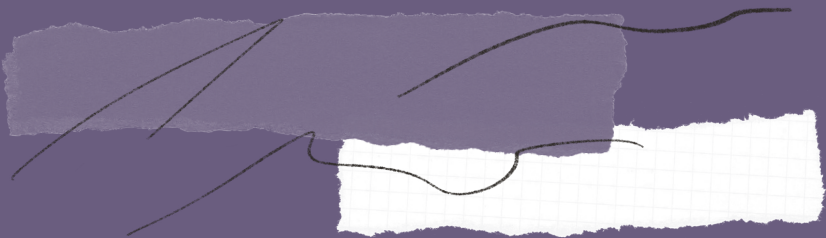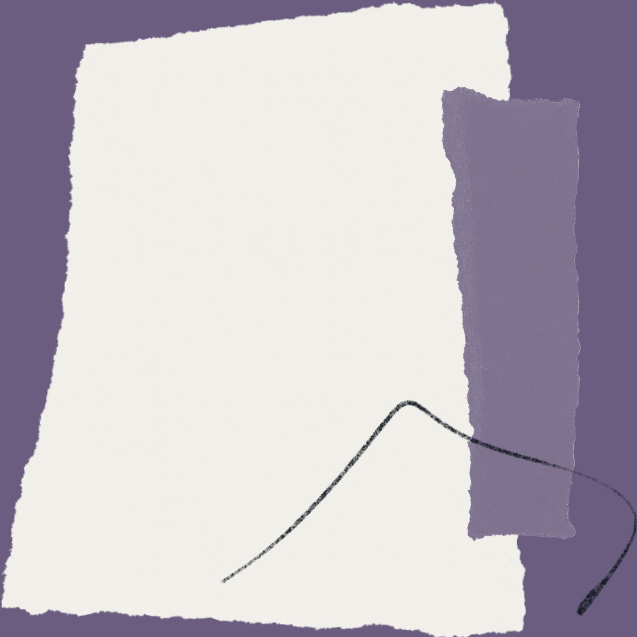
Table of Contents

Editors Notes

Michelle Ruiz & Sachi DeCou

If you're new to the Design Justice Principles, one of our members, Madzia McCutcheon, created this workshop template to support ongoing learning and as a tool to put principles into practice.

figma.com/community/file/1088954285042616622/

We began our work on this zine searching for collective accountability.

At a time when many of us are exploring facets in our relationship with work, we find a tension between inspirational and intimidating when reading the Design Justice principles. A feeling of possible change mixed with "Ok, how?" emerges in regards to application. In the following pages we don't present a concrete way of approaching the questions that arise, but rather unique perspectives that grapple with how to apply the change we want, along with more curiosity. These pieces give us a chance to explore varied facets of living with experiences or thoughts related to Design Justice principles. They specifically provide a space to examine our own experience with ways of thinking or doing the Design Justice Principles in areas where one's work (however that looks) comes into play, and questions that have come up.

In pulling together this zine, many of the themes from our writers were solitary, while reflections from the Principles at Work team and workshops centered around the need for the collective. Whether we arrive at our ideas through storytelling, or challenging power in a meeting - we aim to give these principles room to stretch. **How do we seek out the conditions we need? More importantly, how do we create these conditions together?** The way we manifest action will likely look a bit different for each of us and from one project to the next. How do we share our process? This zine series is one medium we're exploring as a way to engage these questions and new ones that emerge.

Welcome, we invite you to read, explore, write, highlight, scratch out, question, explore your own position and dream. And then, if you're moved to do so, share your experiences back, whatever your medium. We'd love your feedback, and if you're interested in contributing in the future please get in touch.

Justice in the Gray Area

Danny Spitzberg and Yindi Pei
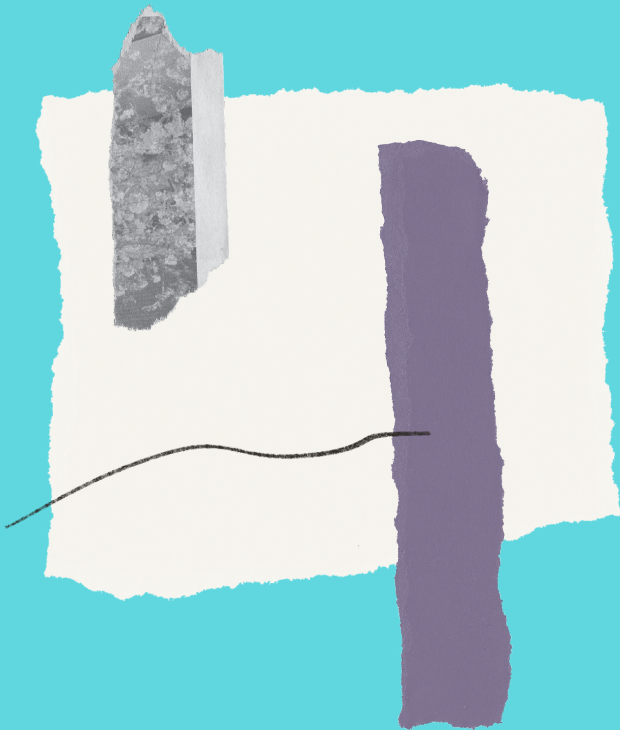
As designers, researchers, and members of communities, we are all on a journey towards justice and liberation.

Some of us are early along the way, having never experienced, imagined, or questioned the injustices of violent, oppressive institutions like TSA, ICE, or CBP.[1] Some of us are organizing against structures of oppression and helping friends and coworkers see how our liberation is bound up together.

But the vast majority of us work in the gray area of corporate, professionalized workplaces where it's difficult to tell right from wrong. It's hard to find who is early on their journey, and who is pushing for change, and who we can look to as co-conspirators in messy situations. How might we apply the Design Justice principles in an auto insurance company?

Our Principles at Work working group takes a Trojan Horse approach to Design Justice. We resist the urge to "throw the book at people" and instead, invest in a patient, nuanced approach to organizing. This story is about how and why we got here, and our journey ahead.

Those of us pushing for change in and outside of the workplace have found that formative moments in experiential learning can help us along our journey. For example, the Design Justice principles emerged from a few dozen engaged designers and researchers at the 2016 Allied Media Conference in Detroit.[2] Over the years, many more have signed on to the Design Justice principles[3] and joined the network as dues-paying members. Some have found inspiration and motivation from beautiful,

---

1 Transportation Security Administration, The U.S. Immigration and Customs Enforcement, U.S. Customs and Border Protection

2 "Generating Shared Principles", Design Justice Network, May 2, 2016.
https://designjustice.org/news-1/2016/05/02/2016-generating-shared-principles.

3 "Signatories", Design Justice Network, accessed on June 16, 2022,
https://designjustice.org/signatories

troubling, and powerful stories. But only a small number of individuals have had a moving, hands-on, collaborative, experience like co-authoring the principles.

Bringing the Design Justice principles to work comes with unique challenges. We might decide to organize a *Design Justice* book club, host a discussion on the matrix of domination, and share the Design Justice principles with our coworkers. But depending on the workplace or company, we might come up against those who find this language alienating or threatening. We might get labeled "that person," which can be a liability for organizing for structural change. Or we might become what Emanuel Moss and Jacob Metcalf call an "ethics owner,"[4] the person in a tech company who holds all of the duty but none of the power to improve policies or operations. These outcomes are all too likely under rainbow capitalism, a term often used to describe how LGBTQ+ symbolism is used by companies in order to sell products without leading to beneficial change for LGBTQ+ communities.[5] What's more, few of us can afford a second, unpaid, job touting Design Justice at work.

With a clear look at the gray area of the professionalized workplace, we have our work cut out for us. The origin of our Principles at Work working group comes from the Q&A at the April 2020 debut of *Design Justice: Community-Led Practices to Build the Worlds We Need*, where one of the 70 people in the audience asked Sasha Costanza-Chock for advice applying the principles in the bland, corporate context of an auto insurance company. Without hearing a satisfying answer, eight collaborators developed a scenario-based workshop where small groups work through design challenges with "no right answer" and come up with new strategies. After two years, nine workshops, and over 800 participants, we estimate that 80% of participants already know a form of design justice — especially from summer jobs, art gallery internships, and entry-level or junior design positions. To share our findings, we co-authored a short paper

4 https://datasociety.net/library/ethics-owners/
5 Zheng, Lily, "Your Rainbow Logo Doesn't Make You an Ally", Harvard Business Review, June 30, 2021, https://hbr.org/2021/06/your-rainbow-logo-doesnt-make-you-an-ally.
6 https://techotherwise.pubpub.org/pub/djnaw/release/2

Our vision for liberation, and the theory of change to get us there, is to grow a non-threatening, plain-language container for experiential learning.

titled "Principles at Work: Applying 'Design Justice' in Professionalized Workplaces"[6] with strategies for individuals (eg, checklists for personal reflection), collectives (finding co-conspirators), and structural-level change (mapping how a company makes major design decisions). Along with our workshop efforts, we've expanded our working group with dozens of collaborators. We have subgroups hosting sessions for reflection on our day job; bringing the workshop to new organizations; evaluating our pedagogy and success; and creating zines. We're currently in the process of restructuring our workshop and changing the name from "Applying Design Justice Principles at Work" to something along the lines of "Critical Design Thinking in the Workplace." For more experiential learning, we might propose to review, rewrite, and re-ratify the Design Justice principles every year or two. This is critical for building practical skills equitably, among peers.

We're on a long journey to apply design justice in the gray area, and we're grateful for friends along the way. This zine is a beautiful example of efforts to orient, equip, and support one another. Nobody has ever formed a union, co-op, or mutual aid initiative with a slide deck, lecture, book, or even a zine alone, but we know that the efforts in which they're created, shared, and used has led to the worlds we need.

Who We Leave Behind

Rosanna Chung

Often times, the groundwork of design justice to uplift and empower marginalized communities are also spearheaded by members of these exact communities. As design justice practices extend into our workplaces, and particularly in large enterprise environments with deeply complex and embedded hierarchical systems, it may be easy to lose critical voices along the way. *Who We Leave Behind* is an illustrative contemplation of this idea – as we continue to progress, we will also need to continually recognize and evaluate the power structures within our workplace processes, and the ones we unknowingly shape as part of creating a more formalized design justice practice at work.

"I think it's easy to get lost in being a nonprofit and assume that our methodology is "doing good," without setting intentional reflection about our positionality and power, and questioning whether we are truly centering the voices of the communities that we aim to 'help'."
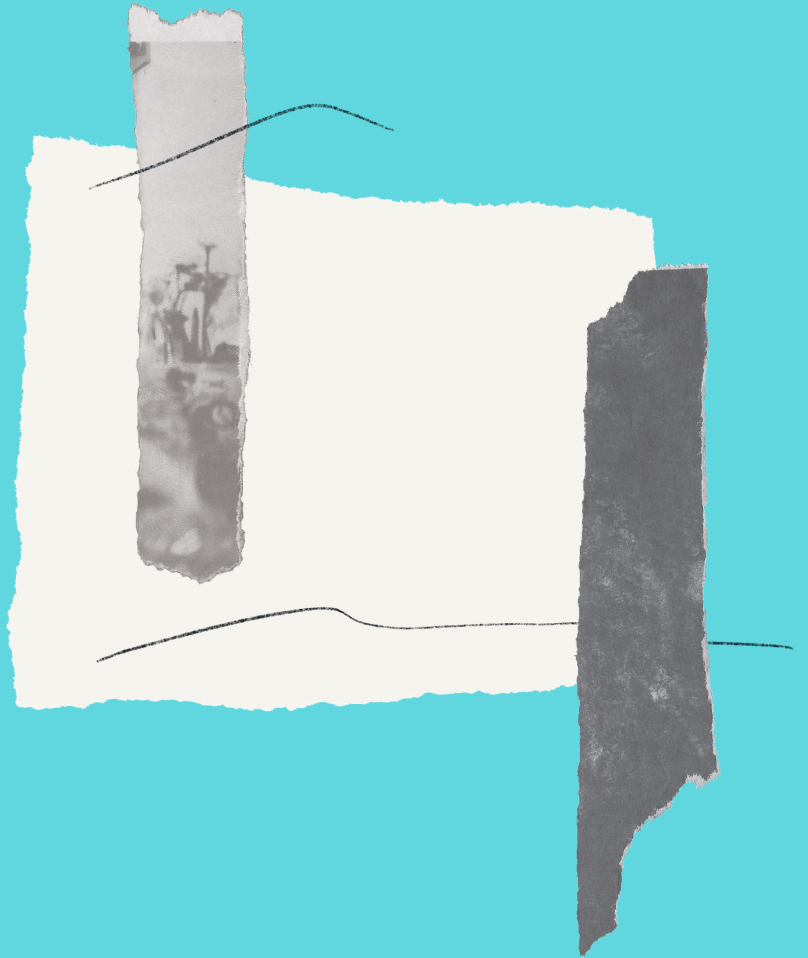
Notes from a Design Justice Principles at Work Workshop

Reflections on Trauma Informed Design

M Strickland
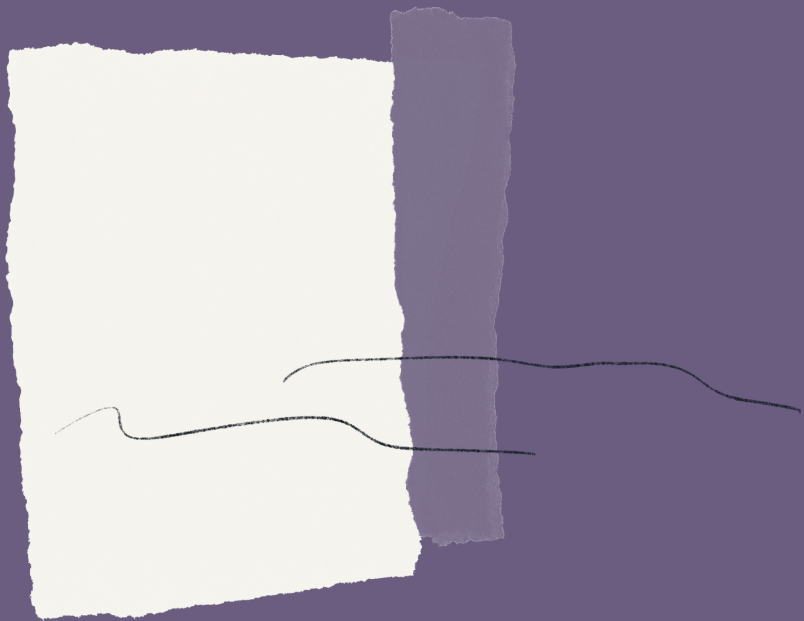
Part 1: Some thoughts and doodles about trauma-informed design research, based on actual (anonymized) user research.
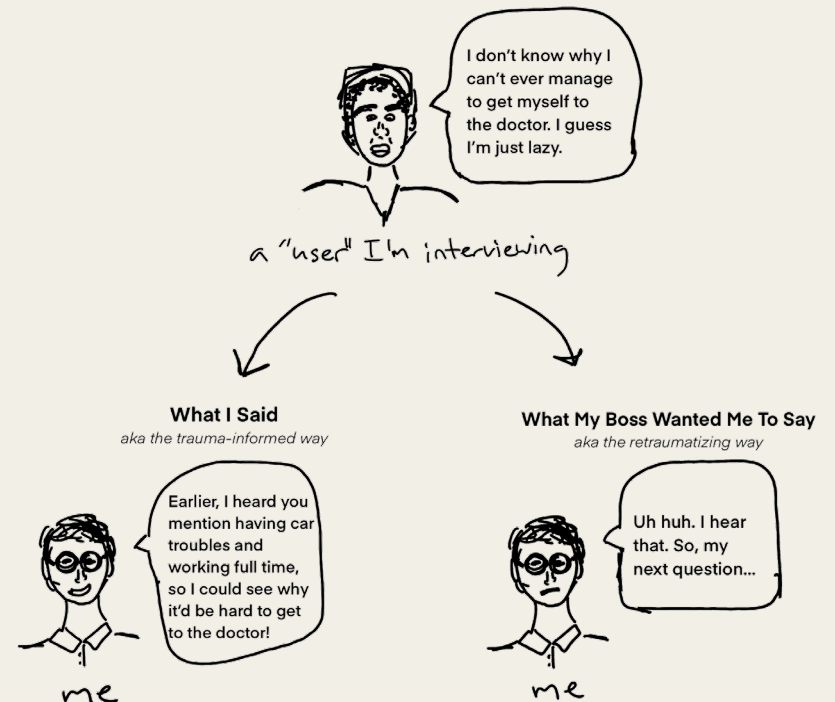
It's been my experience that traumatizing participants is such a normalized part of the design research process that when I take steps to be trauma-informed, it's seen as biasing the data. Here's what this upside down world looked like for me on a recent design research contract of mine.

During this project, I used some of the standard approaches for trauma-informed interviewing, including:

- I occasionally shared relevant personal stories to help equalize the vulnerability dynamic between myself and the participants
- I summarized back to participants what I thought I'd heard them say to help them feel affirmed
- I indicated moments of agreement to establish a connection with the participant
- I mirrored participants' use of language, such as introducing cursing into the conversation if the participant first did so

The client and my boss on the project both gave me "feedback" following my first few interviews. They listed the very set of practices that I had intentionally employed to reduce harm and cited each one as "biasing the data." And yet how can a person who is actively being re-traumatized give "good data?" Isn't it the other way around? Don't we all share more accurate and creative insights when we're feeling affirmed and understood?

Yes, in fact, we do—as I've learned from my teachers of trauma-informed design. If you'd like to learn more about how to incorporate trauma-informed approaches into your design practice, even if it means your boss might (inaccurately) think you're biasing the data, I highly recommend checking out the work of Rachael Dietkus and Sarah Fathallah. As part of an October 2020 gathering convened by the Greater Good Studio in Chicago, they gave an excellent workshop called "Trauma-Informed Design"[1] that you can watch in its entirety on Vimeo.

My other major teacher of trauma informed approaches is the world of harm reduction. Check out your local harm reduction organization (look for the groups in your community that are led by people who use drugs and who do sex work), or check out the U.S. based National Harm Reduction Coalition to learn more.

[1] Greater Good Studio, "Trauma Informed Design", With speakers Rachael Dietkus and Sarah Fathallah, moderated by Sara Cantor Aye, October 8, 2020, https://vimeo.com/466407089.

Within a professional facade that treats re-traumatization as "good data" and connection as "bias," the upside down runs deep.

Part 2: How Social Justice Language Is Used to Justify Harm.
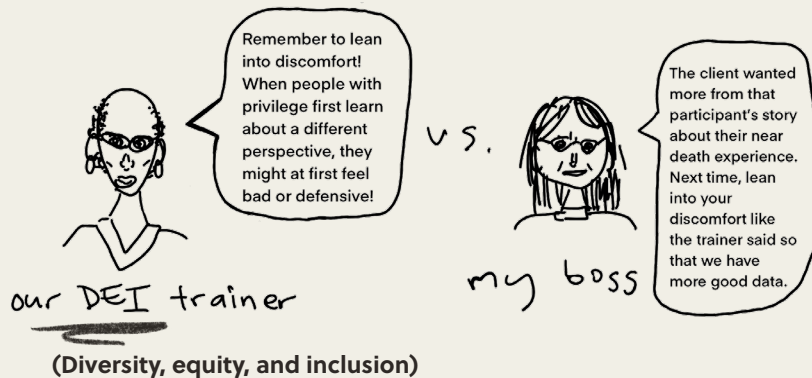
our DEI trainer
(Diversity, equity, and inclusion)

Within a professional facade that treats re-traumatization as "good data" and connection as "bias," the upside down runs deep. On another contract, I was the only trans person on the research team. The project involved conducting interviews about trans discrimination in the work place. Already, this project is turned upside down.

An interview participant told me that they'd probably use different pronouns than the ones they wrote on their intake questionnaire if they felt more supported in their life. My boss, a cis white woman, threatened to fire me for "biasing the data" and being "unaffirming of trans people" when I offered to that participant that I could use pronouns that matched their gender identity during our interview.

And the vertigo continues. While giving me her "feedback," my boss referenced the phrase "lean into discomfort." This wasn't the first time I'd heard the lexicon of social justice and "diversity and inclusion" used as justification for perpetuating harm. On another project, when I chose not to ask any follow up questions after a participant shared an extremely

traumatic story and appeared visibly upset, my boss told me she would "make alternative arrangements" if I refused to conduct the interviews her way (her way being to force participants to re-live their traumas).

Both bosses said to me some version of, "It's important to lean into discomfort!" Excuse me, but what?!? No!!! This is taking a social justice sounding phrase and completely inverting the power dynamics behind its context. When a white person feels discomfort when faced with a Black person's rage at white supremacy, then it's time for the white person to learn how to witness that rage and resist the urge of defensiveness. It's time for the white person in this scenario to lean into discomfort.

But if an interviewer feels uncomfortable about asking a participant a question, perhaps those feelings of discomfort arise because it's their conscience urging them to care for the person in front of them! The voice in the back of an interviewer's head that says, "It feels wrong to ask this question," is not a discomfort to lean into! It's a guiding voice to heed!

The voice in the back of an interviewer's head that says, "It feels wrong to ask this question," is not a discomfort to lean into! It's a guiding voice to heed!

"This work is important and part of it should be about building the network."

"I need fellowship to become confident enough to do this work in my workplace."
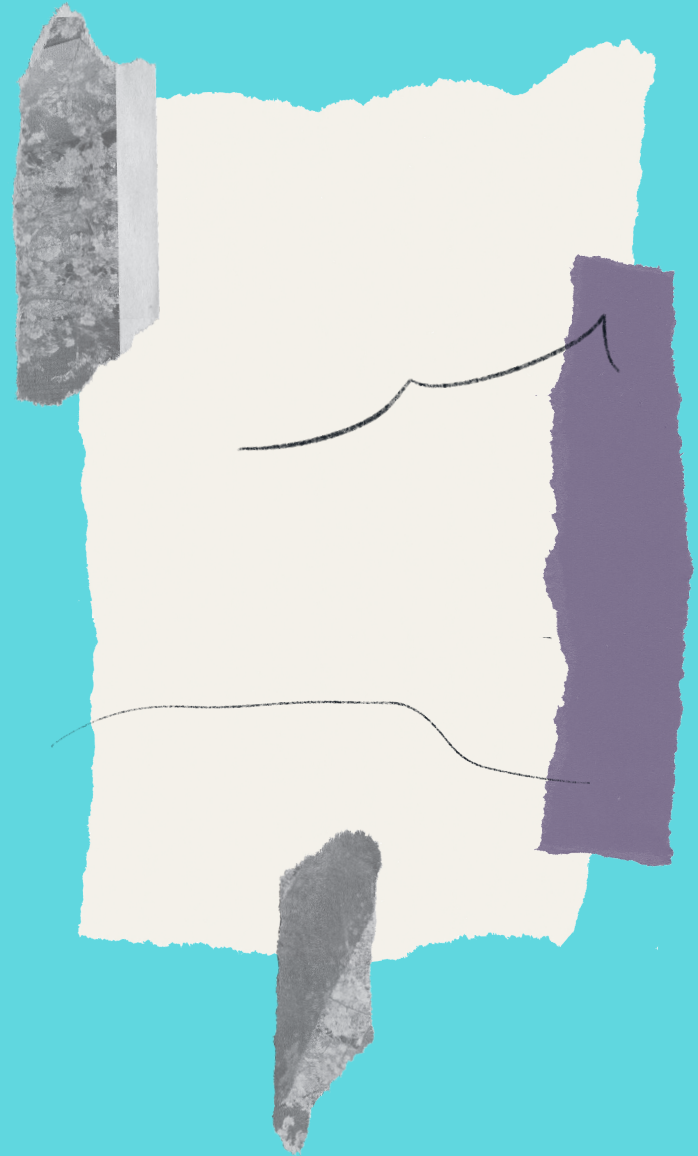
Notes from a Design Justice Principles at Work Workshop

Community Caution

Jhono Bennett

This article is an adaptation and excerpt from an article written in Just Spatial Design ZA. The original article can be found here: justspatialdesignza.com/2020/10/19/caution-with-community/.

"... the **community** protested against..."

"... the **community** built this structure..."

"... this project exemplifies **community** architecture..."

"... the **community** agreed with..."

When one reads the sentences captured in the above picture, hears these phrases, or even shares these words in your practice or institutional spaces, a particular set of images, ideas, and actions are brought to mind. Perhaps a smiling, but determined woman carrying a heavy load; a group of laughing children playing in a desolate street; maybe a modest - but proud - homeowner standing against a 'humble' dwelling as the sun sets in the distance...[1]

---

[1] Davis, R.2015. Being the Best White, and Other Anxious Delusions. Pan Macmillan, South Africa

many communities & individuals

a community?

a community?

a community?

a community?

a community?

a community?

a community?

a community?

a community?

a community?

a community?
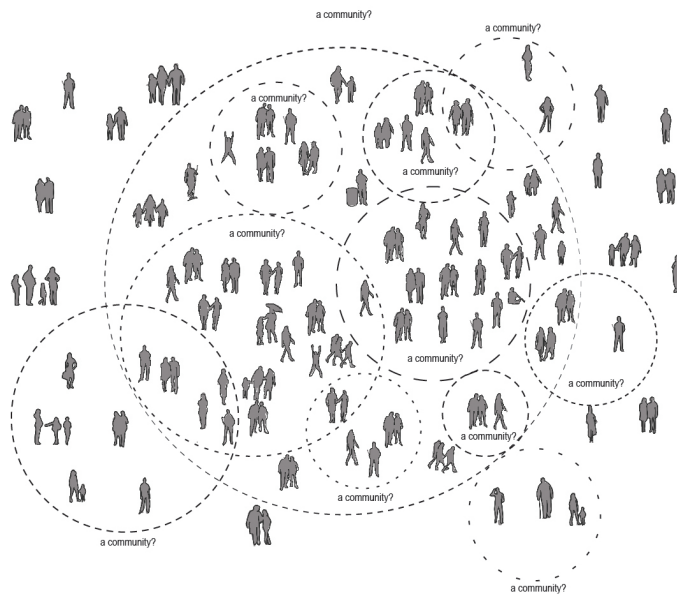
a community?

The answer to this question would largely be dependent on your social upbringing, your experiences growing up and your demographic background. As a South African, I would argue that when we generally talk about 'community', we are at some level describing a tightly knit group of similar people: most likely economically struggling, bound together through difficult social or cultural circumstance and working together to overcome a series of socio-economic circumstances and events set in a deeply unequal world. In the South African context, I would argue that when we use this term we are describing a group of people who are primarily not white presenting and who face discrimination or disadvantage on some societal level.

Through my experiences as a South African, an urban researcher and a spatial design practitioner; I find that there is an uncritical use of the concept of 'community': a reductionist, intersectionally myopic and generally unhelpful - and sometimes romantic - version of this concept that I have seen employed across various political, social, civic, and even corporate marketing initiatives. Often these narratives focus on a particular image of unanimous cohesion, dire vulnerability and optimistic hints of hope for those affected by South Africa's legacy of spatial inequality. To what end? This is an important question, and one I suspect I will find myself working through for the remainder of my practice/career.

I *do not* for one moment deny that the values of social cohesion and collective identity exist across the many groupings of socially and spatially marginalized people. I believe strongly in the power of any grouping of people's cohesion towards not only overcoming difficult circumstance but to changing whole societies[2]. I recognize that this term, when used with integrity, clarity and intent to describe and celebrate actual 'communities' is an important acknowledgment of people's collective identities and can be a powerful call to arms for social and grassroots movements[3]. In addition, I recognize that in South Africa - and I'm sure in other socially fragmented spaces - we are often speaking between languages, cultural norms and in general certain words and terms are inherently multi-faceted and can cover overlapping concepts.

This article is not meant to dissuade anyone from using the term community, but rather to better articulate the nature and complexity that makes up this type work and to offer some possible ideas on how those of us working in this sector can work through this complexity more effectively and responsibly.

---

[2] This belief is a founding principle of the organization I co-founded in 2010: 1to1 – Agency of Engagement.
[3] Guijt, I. & Shah, M.K. Eds. 1999. The Myth of community: gender issues in participatory development. New Delhi: Vistaar Publications.

Ok, I get it. Now what?

I don't feel that 'community' as a concept doesn't exist or that we should not use this term in practice. My concern lies in the way people with societal power use 'community' to further their own misreading or re-enforce unhealthy and often damaging framings of people and their cohesion. In particular, I am concerned with how 'community' is used in spatial design practice in the built environment and how this un-challenged term often reflects unconscious bias that results in ill-considered buildings, programmes or spatial strategies. In that context the idea of 'community' is used to imbue the proposal with pre-existing and external values of what a 'community' should look like, want or even

My concern lies in the way people with societal power use 'community' to further their own misreading or re-enforce unhealthy and often damaging framings of people and their cohesion.

need, resulting in some of the 'white elephant' infrastructures we see here in South Africa. This infrastructure then goes on to be celebrated through media outlets and the year-end reports of NGO's[4]. While this is a critique of the term 'community' and the way it is often used, it does not mean that practitioners, designers and organizers cannot work in ways that are inclusive, and that include and center people and communities in any spatial or design process.

My questions (and continuous self-challenge) for those that see value in this discussion are summarized in the following provocations:

1. Can we adopt and normalize a more complex idea of 'community' being multiple communities and individuals who share space?
2. When we say or think 'community', can we allow for people to question what we mean by that towards a better understanding of a context?
3. Can we be more specific to describe what we mean? Is it a neighborhood, a group of men/women/children, the church goers, the football players, etc. This might allow your designs more variables to draw from.
4. How can we meaningfully recognise and value the project beneficiaries and adjacent grass-roots actors in projects in ways that offer support financially, experientially, and creatively?

This article has been developed closely with peers in the field who believe in the importance of inclusive approaches to spatial development but are equally as frustrated by the way in which this work is seen and practiced in South Africa. In particular, this article is directed at my fellow white-identifying - alongside other privileged spatial design practitioners - who, like me, grew up in a context that did not support productive self-criticality and ignored important nuances in how we both understand ourselves and those we engage with.

---

[4] I urge you to enjoy the satirical Dick & Rick: A Visual Primer for Social Impact Design
http://welcometocup.org/Projects/TechnicalAssistance/DickRick

For Lack of Nuance

Saba Sinha
Collage by Erika Díaz Gómez

Why a commitment to sustainability requires the same to diversity and inclusion

I am a Designer/Strategist in Sweden, and circular business models, sustainable design and impact driven strategy are no longer uncommon specialisations for design consultants. Having said that, what I do find less common is a nuanced thought process, that considers not just the surface of the problem but proceeds to understand related layers. I miss perspective.

I come from a country that produces things cheaply and exports them to countries like Sweden. Fast fashion, electronics, hand loomed goods, leather, plastic products and a hundred other things.

Not without consequence.

I grew up watching the river in my city dry up and turn into a sewage channel, full of toxic chemicals from factories around that produce all kinds of stuff. I watched the banks that we used to picnic on, turn caustic. I grew up eating vegetables irrigated by that water, then stopped buying them as I learnt of the rising amount of harmful chemicals in the river. At the same time I saw local farmers lose their livelihood.

And these are just the overt effects, I am not even going into the state of garment factory workers, or the situation further down the supply chain, where materials are farmed and procured.

The other side of the same city also has several flea markets, where these clothes end up, once bought, discarded, donated and then sent to be recycled. The sellers call them 'factory rejects', perhaps a portion of it is too. That is definitely a better narrative to sell.

They are sold dirt cheap, they look good and often also have their brand labels intact. My sisters and I grew up wearing them. We still do. I never really had a problem with them, until I read enough to uncover the layers of why they're there, and how they affect the local small and medium industries.

So, when I say that I miss perspective or nuanced thought, I mean the ability and desire to understand and engage with issues that might not have direct impact at the user/ consumer end in Sweden, but are part of the processes that have a massive impact on several layers beyond the surface: on people, households, environments, economies involved in producing and putting that product on your table, or in disposing it once you're done with it. Ones much like the city I grew up in.

How do we ensure nuance, the ability to engage with issues beyond just the surface? I don't think I have the complete answer, but I do believe it would start at intent, empathy and diversity.

I particularly like the example of the garment industry, because the solution, for years, has been so surface level/ end of line.

Recycling, and donating are fantastic ways to make room for buying more, and for getting rid of the guilt that comes with it, with a dash of nobility and goodwill. The uptake is massive. I know most western countries have clothing recycling and donation stations available in every neighbourhood.

I'm not saying that it was never a good solution, but at this point around 56 million tonnes of clothing are bought each year, and only 12% of the material used for clothing ends up being recycled, globally. You can imagine what goes into producing all of it, the amount of clothing discarded regularly, and what happens to it.

Collage by Erika Díaz Gómez

Now, I have sat in ideation workshops, had lunch table conversations with colleagues in Sweden, where donating and sending clothes for recycling as a solution is praised and used as inspiration when talking about ways to reduce the carbon footprint or waste created. And this is where I think there is a need for nuanced thought, diverse perspective, and frankly, the desire or motivation to understand and engage with the challenge beyond the surface.

Let's look at, for example, a garment company in a western country. Imagine the perspective, context, and layered empathy a designer like myself can bring into a room full of people who are looking for 'sustainable' ideas, solutions, models, and frameworks.

Most people in that hypothetical room will be extremely well intentioned, they would have stacks of information, hoards of data. A person like me would probably not be the smartest, sharpest or most experienced in terms of the business.

A person like me, however, would be an immigrant, woman of colour designer, who grew up in a very different context, who has the possibility to see the problem and empathise with the outcomes of it in a very different way, on a very different plane. And who can push the rest of the team, ask questions, and contribute to the way the problem is approached. Just as an example, a person like me might scope and steer the discovery and research phases differently, look for insights in places where others might not, which would then affect the outcome.

If this makes sense, I don't think I need to underline or press upon the need and value of diversity and inclusion in the world of design, especially in high-income countries, that hold the power to bring about large scale changes. Include and design with people who see and experience the world or a challenge differently from you.

Because if you're serious about sustainability and impact, surface level and end of line solutions won't really cut it. And the only way to create worthwhile, holistic, sustainable solutions that can actually drive impact, is to include people from diverse backgrounds, cultures, experiences. To give them equal seats at the table, space to share what they know and think. To band together, collaborate, and co-create.

The only way to create worthwhile, holistic, sustainable solutions that can actually drive impact, is to include people from diverse backgrounds, cultures, experiences.

"Reminder that power mapping is important for ~~taking action~~ in my work, not just in organizing on the outside!"

"I'm constantly learning how to work against power dynamics with the communities of folks we want to center in our work."
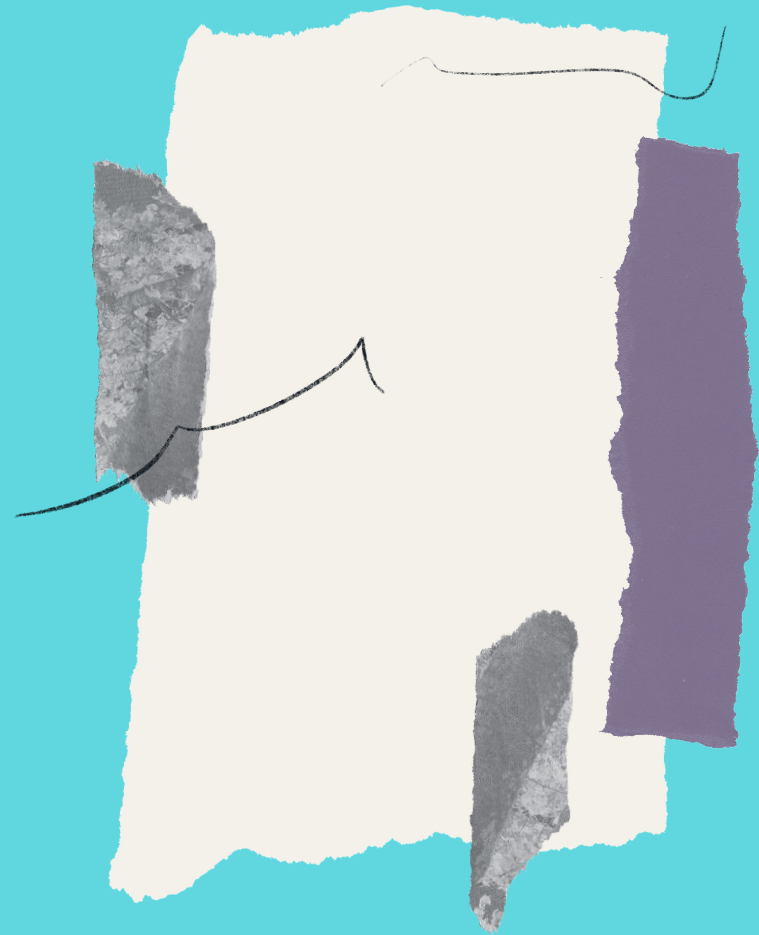
Notes from a Design Justice Principles at Work Workshop

Non-extractive Research Methods

Anushka Jajodia

Who is writing?
Anushka Jajodia, she/her, born in a Hindu-identifying family in Mumbai, India (aware of my caste and religion privilege), pansexual
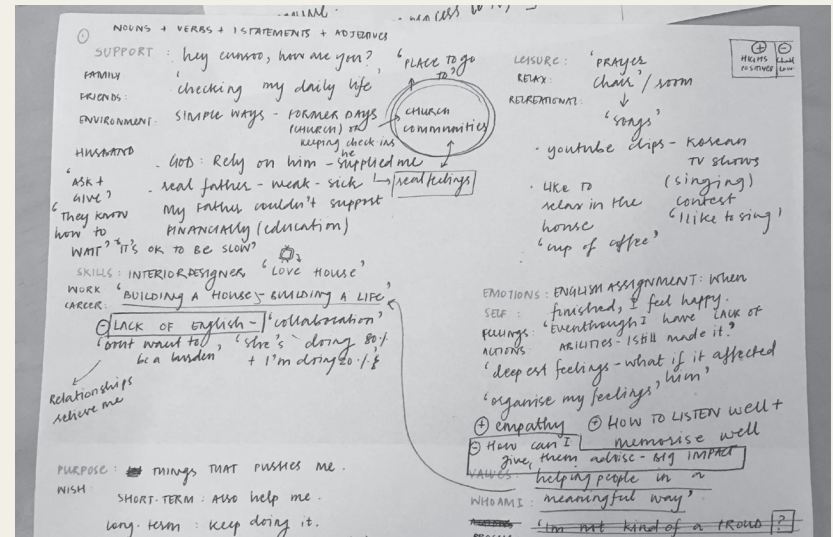
What are my interests?
Design research, community-based participatory research, anti-oppressive practices, storytelling, visual design, illustration, tabla playing

Who is the audience for this piece?
Researchers, academics, "professionals" living in the status quo

Storytelling as a Non-Extractive Research Method

Storytelling is used increasingly as a research method in disciplines like healthcare, non-profit, government, design, etc. Storytelling has also become a buzzword and a product associated with shallow marketing campaigns in professional spaces, influenced by the monopolization of entertainment media and corporate brand storytelling[1].

Thus, it is crucial to embody non-extractive guiding principles and values if the goal is to use storytelling as a research method to do liberatory work. I write this piece to acknowledge the Indigenous non-extractive application of storytelling that has existed for generations and strive to decolonize research.

[1] https://slate.com/podcasts/decoder-ring/2022/05/how-storytelling-became-a-product-and-where-it-goes-from-here

Any research method, including the storytelling method, may not always be practiced in a non-extractive way. An individual or team would have to consciously learn and discuss what 'extractive' means and to what extent they are ready to challenge ways that this may diverge from the expectations of a client, team, or boss. One way I have learned to discuss with a team is to clarify the research benefits at the very beginning:

1. benefits to participants and community,
2. benefits to a researcher, and
3. benefits to research

Why is this important? Because if the intentions, actions, and decisions are inclining towards benefiting the research and researchers only, then it's probably pointless and performative to assume one practiced a non-extractive method. What do you feel?

What follows is a collection of excerpts from various scholars, the majority of them being Black and Indigenous scholars, by whom I remain inspired and whose voices guide my life work. I hope to highlight some of their work and values as they deepen and support the conversation to use storytelling as a non-extractive research method.

• Ranjan Datta shares, *"Indigenous cultural storytelling is one of the notable ways of knowing the world... it is a culturally appropriate research tool for building relational engagement and sharing imagination, dreams, and initiatives with participants."* He explains, *"storytelling is not only about sharing personal stories; it is also a... mode of engagement regarding how we want to be [authentically] seen as researchers by our participants' community... as well as how we can contribute to change."*[2]

• He expresses, *"My stories are practice; they are very much alive. My stories always remind me of who I am and my responsibilities toward my research participants. I use my personal stories to remind me of my responsibilities as a researcher, centering my participants' voices as they walk forward into an unknown sphere of academia. They say, 'Here we are and we are walking into your space. Make way and don't hinder because we have a story to tell; our story is also your story.' Therefore, I see traditional storytelling as an intergenerational space where children, youth, and adults connect with each other."*[3]

As I sit with his stories, I value how storytelling can be a caring way for researchers and participants to collaborate as equal partners. I further wonder, isn't it ironic to refer to some people as 'participants' and some as 'researchers' when there's a deep two-way exchange of energy and wisdom?

• I admire the reflection and questions that Ranjan Datta asks himself as a researcher, *"As a researcher using the storytelling method, understanding the questions, Who am I? Where did I come from? is important. Personal stories can provide a deeper explanation of who I am personally, professionally, emotionally, and spiritually as a researcher."*[4]

Positionality matters.

• Linda H. Humes writes, *"Acknowledge the identity, character, history of researcher as integral components in listening, selecting, interpreting, and composing the story. The researcher must be concerned with their relationship with participants to the extent to which they self-position as an outsider or insider. (An insider positionality is a benefit to the researcher because it develops increased connectedness with the subject - leading to greater trust)."*[5]

---

[2] Datta, Ranjan. "Traditional Storytelling: An Effective Indigenous Research Methodology and Its Implications for Environmental Research." AlterNative: An International Journal of Indigenous Peoples 14, no. 1 (March 2018): 35–44. https://doi.org/10.1177/1177180117741351.

[3] Datta, "Traditional Storytelling: An Effective...", 35-44.
[4] Datta, "Traditional Storytelling: An Effective...", 35-44.
[5] Humes, Linda H., "African American Storytelling: A Vehicle for Providing Culturally Relevant Education in Urban Public Schools in the United States" (2016). Education Doctoral. Paper 264.

While sharing stories is foundational, researchers and participants must design the research process together and clarify for example: What method(s) is appropriate to collect stories? What's the purpose of the method(s)?

- Inspired by Ranjan Datta, I understand that methods are not to be randomly selected, but rather *"to preserve voices, build resistance to dominant narratives, create politcal integrity, and... strengthen the community."*[6]

- Kirsten Keene, Kim Keating, and Pirkko Ahonen list different methods to build capacity and ownership among participants:

    + Visual, Auditory, and Performance-Based Methods[7]
      Photovoice, Digital Storytelling, Scrapbooking, Story Quilting, Theater

    + Individual and Group Interview Methods[7]
      Participant Interviews, Oral History/Community Interviews, Story Circles

- I was drawn to Andrews and Beer's article that challenged the prevailing discourse that older people are passive recipients of care with nothing to give. They creatively engaged with older adults with dementia in research studies and shared, *"Create an environment where two people bring all of 'who and what they are' into the present moment. Trust that they will co-create something that neither would have expected without the other."*[4] Further, *"I sat with him in his space, allowing him to shape what we did together. Before we even got to the stage of interviewing, we sat for long periods of time, sometimes not even speaking. From these quiet beginnings, his story began to emerge."*[8]

---

[6] Datta, "Traditional Storytelling: An Effective...", 35-44.

[7] Keene, K., Keating, K., & Ahonen, P. (2016). The Power of Stories: Enriching Program Research and Reporting. OPRE Report# 2016-32a. Washington, DC: Office of Planning, Research and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services.

[8] Andrews, Nick, and Cheryl Beer. "The Story of Georgie Muscles: A Narrative Approach to Nurturing Well-Being and Evidence-Enriched Practice in Health and Social Care." Storytelling, Self, Society, vol. 15, no. 1, Wayne State University Press, 2019, pp. 92–107, https://doi.org/10.13110/storselfsoci.15.1.0092.

As I sit with his stories, I value how storytelling can be a caring way for researchers and participants to collaborate as equal partners. I further wonder, isn't it ironic to refer to some people as 'participants' and some as 'researchers' when there's a deep two-way exchange of energy and wisdom?

The focus on the life story of one older person with dementia warmed my heart because he was seen as a whole person and storyteller with his strengths, which often is rare for older adults experiencing dementia.

He went from feeling "useless" and "unworthy" at the beginning, to feeling "confident" and "strong" by the end of the research. I'm part of a research team that focuses on providing dementia education to Korean elders in the USA and their caregivers. Thus, this article was like a gift and portal for me to question the stereotypical notions even running among our team that older adults with dementia are incapable of engaging or sharing their stories enough.

- Conversely, there may always be people who choose what to share, and Ranjan Datta notes Wilson's expression that *"some stories, because of their sacredness, should not be revealed because this strips them of their spiritual and sacred elements."*[9]

- Kirsten Keene, Kim Keating, and Pirkko Ahonen further emphasize that, *"Stories are deeply personal, and storytellers' rights must be honored. Potential storytellers need to be engaged from start to finish in conversations about the story analysis, collection purpose, safety, confidentiality, data ownership, verification, and approval to share stories."*[10]

- Dissemination of research findings or research journey as an integral part of the research was highlighted in the article written by Andrews and Beers: *"The dissemination of his work was as important as the creation of it, in terms of empowering his memory of self. This way, research findings are not something we merely take from people with dementia to serve a greater good, research is a reciprocal person-centered methodology from start to end."*[11]

- Andrews and Beers state a much-needed perspective on why focusing on storytelling, dialogue, and value-centered is crucial, *"When people truly meet, through sharing and engaging with stories through dialogue, they are never quite the same again... We think there is a message here for the social science research community, whose members seek to create "impact," but often wrap up their research in complicated language and detached scientific rationalism... it will continue to lose credibility while it clings to scientific rationality... now is the time for values rationality."*[12]

There is so much to learn from Indigenous, Black, and Dalit literature and storytelling. I have limited knowledge, and am slowly diving into stories and writings by Dr. Babasaheb Ambedkar and Octavia Butler, etc. I may not even know the existence of magnificent storytellers due to my birth and caste location, but I am determined to unlearn and learn.

---

[9] Datta, "Traditional Storytelling: An Effective...", 35-44.
[10] Keene, K., Keating, K., & Ahonen, P., "The Power of Stories".
[11] Andrews and Beer. "The Story of Georgie...".

[12] Andrews and Beer. "The Story of Georgie...".

Case Example: Nurse-led research intervention at the Hopkins PROMOTE Center (Johns Hopkins School of Nursing)

The Caregiver Support research program is a multicomponent strengths-based intervention. It is nurse-led and designed to improve the quality of life of caregivers who take care of patients with advanced heart failure. The 16-week intervention is led by a nurse and consists of five virtual visits with five interim phone calls to evaluate goal attainment progress.

Throughout the research process, the team focuses on understanding the caregiver as a whole person, respecting the experiential, cultural, and spiritual knowledge they bring. Virtual visits are designed to support caregivers as active collaborators, storytellers, and advocates for their healing and well-being. It's a way to hold space for caregivers to identify personal and collective health goals creatively.

'Purpose in Life' is one of the main themes for the research and visits. Caregivers are presented with 4 categories of cards that include discussion prompts. The categories include:
* Caring for Yourself
* Experience as a Caregiver
* Purpose
* Emotions
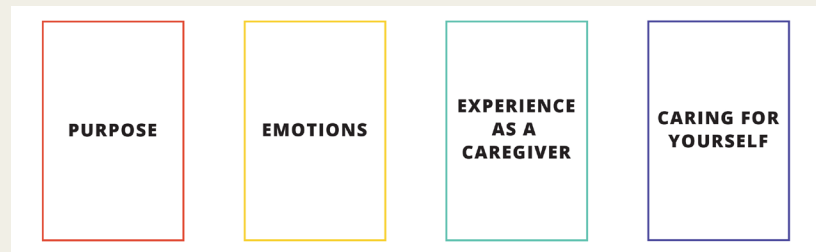
The caregiver selects a card to begin the discussion. During the discussion, the nurse uses a note-taking worksheet to document stories shared by the caregiver.

After the visit, the nurse synthesizes key stories, feelings, and observations. At the next visit, the nurse shares the synthesis and asks for feedback and additional input from the caregiver. Then they co-create a list of important values from the sense-making. The caregiver is encouraged to pick three values to craft their purpose statements. Eventually, the nurse and caregiver discuss and set achievable goals that contribute to a sense of purpose inspired by and based on the purpose statements.

Purpose Statements from Caregivers:

* *'My purpose is to prioritize my own self-care by asking kids to come stay with my husband, so I can get out and do something once every 2 weeks for 2-3 hours'*

* *'I hope that I am able to live a full life surrounded by people that I love and that we are able to form a warm, genuine connection while spending quality time doing the things we enjoy.'*

[Note: We engaged the research team and care team to co-design intervention processes and materials.]
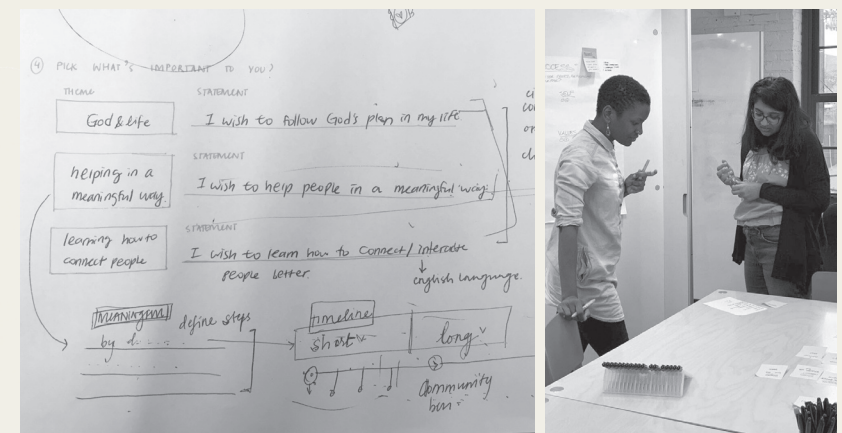
Contributors

Anushka Jajodia • www.anushkajajodia.com
Anushka Jajodia is moving through time as a social justice-centered designer, practicing participatory design research and storytelling through visual design and illustration. She currently works with a team of researchers, clinicians, and public health experts to support the well-being of older adults and their families. She is determined to learn, participate in and support the collective work toward caste abolition.

Danny Spitzberg • twitter.com/daspitzberg
Danny is a user researcher for a cooperative economy, living on unceded Huichin Ohlone land. He facilitates worker-led research with a staffing co-op, and is a co-organizer in the DJN Principles at Work working group.

Erika Díaz Gómez • IG @pues_adios
Erika Díaz Gómez is a Colombian Design Research Lead and an analog collage artist (IG @pues_adios). She is committed to design processes that invite the least privileged to occupy spaces of influence, as a first step to creatively dismantle systems of injustice and oppression.

Jhono Bennett • www.jhonobennett.co.za • www.1to1.org.za
Jhono Bennett is the co-founder of 1to1 - Agency of Engagement, a design-led social enterprise based in Johannesburg, South Africa. His practice-led research, interests are driven by issues of inclusive design approaches, spatial justice, critical positionality, and urban planning in South African cities.

M Strickland • www.curbcutdesign.studio
M Strickland is a design researcher in Washington, DC. They refer to their design practice as Curb Cut Design Studio to honor the principles of universal design that guide them.

Madzia McCutcheon • www.wildmagia.ca
Madzia is a product designer based in Montréal, Québec. Currently, she is designing for Officevibe, an employee experience platform that aims to improve team engagement, recognition, and alignment.

Rosanna Chung • www.rosannachung.com
Rosanna is a Chinese-Canadian designer based in Toronto, Canada. Currently working in the intersection of design and tech, she's interested in visual design systems and information visualization.

Saba Sinha • sinha.saba@gmail.com
Saba is a design thinker, who works with areas like Service/ Experience design, Product, Innovation and Transformation, with a focus on impact centred design and sustainable development. Born and raised in India, she worked in Delhi before moving to Stockholm in 2015.

Yindi Pei • twitter.com/yindithey
From their home on stolen Huichin Ohlone land, Yindi spends their unpaid time thinking deeply about cultivating caring communities on rematriated land and "rest as resistance." They also co-organize in the DJN Principles at Work working group.

Principles at Work
DesignJusticeNetwork.org