

Participatory Design Practices in Mental Health in the UK: Rebutting the Optimism

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- 1 Peter Bradwell and Sarah Marr, *Making the Most of Collaboration: An International Survey of Public Service Co-design* (London: Demos Report, 2008); and Elizabeth B.N. Sanders and Pieter Jan Stappers, "Co-Creation and the New Landscapes of Design," *Co-Design* 4, no.11 (2008): 5–18.
- 2 Edward Andersson, Sam McLean, Metin Parlak, Gabrielle Melvin, *From Fairy Tale to Reality: Dispelling the Myths Around Citizen Engagement* (London: Involve and RSA, 2013), <http://www.involve.org.uk/wp-content/uploads/2013/02/From-Fairy-Tale-to-Reality.pdf> (accessed February 2014).
- 3 The title of the 2016 Participatory Design Conference in Aarhus was "Participating in an Era of Participation."
- 4 Hillary Cottam and Charles Leadbeater, *Health: Co-Creating Services* (London: Design Council, 2004), http://www.hilarycottam.com/wp-content/uploads/2010/01/RED_Paper-01-Health_Co-creating_services.pdf (accessed November 2013).
- 5 See Design Commission, *Designing Democracy: How Designers Are Changing Democratic Spaces and Processes* (London: Design Commission, 2015), http://www.policyconnect.org.uk/apdig/sites/site_apdig/files/report/497/fieldreportdownload/designingdemocracyinquiry.pdf (accessed November 2015); Geoff Mulgan, *Design in Public and Social Innovation: What Works and What Could Work Better* (London: NESTA, 2014), https://www.nesta.org.uk/sites/default/files/design_in_public_and_social_innovation.pdf (accessed March 2014); Christian Bason, *Design for Policy* (England: Gower, 2014); and Design Commission, *Restarting Britain 2: Design and Public Services* (London 2013), http://www.policyconnect.org.uk/apdig/sites/site_apdig/files/report/164/fieldreport

Introduction

Especially in its more collaborative forms, design seems to be increasingly celebrated by governments worldwide for its potential to address the complex challenges of society.¹ By including different perspectives and providing a fresh language and tools, design is seen as an alternative to more traditional methods of citizen engagement and policy making that are probably perceived as old-fashioned, convoluted, and maybe even *boring*.²

In what has been defined as an "era of participation,"³ design practices seem to have become very central to the process of making publics and bringing to life the dream of developing new public services and new ways of political engagement:

In the 20th century, public goods were produced by professionals working in dedicated, hierarchical organizations, delivering packets of service to waiting, deferential users: doctors made you better, teachers provided education, police caught criminals. In the 21st century, public goods and services will be created interactively, through partnerships between professionals and users, and by user collaboratives.⁴

The overly optimistic tone of the RED Unit paper in describing the twenty-first century publics has been reinforced since 2004 by many other articles, publications, and case studies that have been selling the role of design in public and community organizations as the panacea to all problems. These authors and papers, even the most critical ones, all reproduce a discourse about design for social change that tells a single story of design,⁵ in which the latter is usually uncritically depicted as an effective way to understand the human experience, to increase creativity, to quickly learn "by doing" and "by failing fast," to engage stakeholders in collaborative efforts, and to revolutionize public services and contribute to opening up bureaucracies.

download/designcommissionreport-restartingbritain2-designpublicservices.pdf (accessed November 2013).

- 6 In the field of mental health, a strong distinction is made between the so-called “medical model” of mental health and the “social model.” The medical model frames mental health as a medical condition and an illness. (See Peter Beresford, Mary Nettle, and Rebecca Perring, *Towards a Social Model of Madness and Distress? Exploring What Service Users Say* (London: Joseph Rowntree Foundation, 2010.) Meanwhile, the idea of the “social model” (which originally comes from the disabled people’s movement) tries to shift the blame and responsibility from the individual to the societal level by framing “disability” and mental health as a discriminatory and oppressive response to seeing people as having an impairment.
- 7 Simon Blyth and Lucy Kimbell, *Design Thinking and the Big Society: From Solving Personal Troubles to Designing Social Problems: An Essay Exploring What Design Can Offer Those Working on Social Problems and How It Needs to Change* (United Kingdom: Actant and Taylor Haig, 2011), <http://actant.co/publications/designing-thinking-and-the-big-society-from-solving-personal-troubles-to-designing-social-problems/> (accessed July 2014).
- 8 See, e.g., Katie Collins and Mary Rose Cook, “Ethics of Participation Within Service Design,” in *Mapping and Developing Service Design Research in the UK*, Daniela Sangiorgi, Alison Prendiville, and Amy Ricketts, (UK: AHRC, 2014); and Claus Bossen, Christian Dindler, and Ole Sejer Iversen, “Impediments to User Gains: Experiences from a Critical Participatory Design Project,” *Proceedings from the 12th Participatory Design Conference: Research Papers - Volume 1* (2012), 31, 40.
- 9 Alan Cribb and Sharon Gewirtz, “New Welfare Ethics and the Remaking of Moral Identities in an Era of User Involvement,” *Globalisation, Societies and Education* 10 (2012): 507–17.

The question that comes to mind, when reading these accounts of design, is this: When and where did design build the credibility and provide the credentials to do this demanding job? The described design process sometimes feels quite distant from my direct experience of working collaboratively with different actors in communities and in the mental health system in the United Kingdom, where funding has been squeezed to the minimum and asymmetry of power persists in a medical model of society.⁶ The design process, so positively described in these accounts, appears to be a practice that *designs out* conflict and dissent and, at best, makes the failing public services look more palatable.⁷

In this essay I focus on the participatory element of design when used in the mental health sector. I build on my reflections from my professional practice, problematizing the role and the meaning of participatory encounters and the complex dynamics of exclusion and *self*-exclusion that are at play. I start by introducing the idea of participation as a paradox and then look critically at the value of agonistic models of participation. I propose two alternative approaches with which I am currently experimenting.

There are two notes for the readers to keep in mind as they read through the essay: The first is that all the work in my practice results from a group and team endeavor; the second is that the goal of this paper is not to offer a blueprint or a model (if that can even exist) for participation or political engagement, but to allow my attempts, challenges, and frustrations to resonate with the readers’ own experience of doing political participatory design work.

The Paradox of Participation

Discourses of participation in design often fail to represent the ethical complexities of working in a collaborative way.⁸ This neglect is especially apparent in the context of social welfare relationships—and in mental health in the United Kingdom in particular, where individualist forms of involvement are privileged over more relational and political ones.

For example, within the tradition of service users’ engagement, a clear script is followed, which Cribb and Gewirtz define as the script of the “compliant participant.”⁹ Here, certain types of participation are encouraged and requested from individuals; meanwhile, others types—like people getting together to protest against the quality of care they receive or against the cuts to public services—either are not encouraged or are actively discouraged. As Cribb and Gewirtz suggest, then, what is expected is not participation tout-court but a well-defined type of participation that responds to specific moral imperatives and raises specific normative expectations.

If participants do not align, they are at risk of being constructed as irresponsible, or disengaged, or somehow wrongly engaged.

What, then, are we really talking about when we talk about participation in design? Many scholars argue that participation is a sort of *paradox* in that it always exists as an ambition, but it can probably never be realized.¹⁰ I have encountered this paradox of participation, also described as a paradox of enablement, many times in my practice, working within the mental health system and in the frustrating position of witnessing the disempowering effects that prolonged inequality can generate on people: a sense that they are in need of help, that they are not well enough to know what is best for themselves, and that they are not in the position to take control and make decisions or shape their lives. What the paradox of participation says in practice is that, in assuming equal agency (e.g., in co-design workshops, where people are equally sitting around the table and hence presumably contributing equally to the discussion), *de facto* participatory design interventions marginalize the people they are designed to help.

Beyond the Agonistic Model of Participation in Design

A more interesting way of framing participation in all its complexity, and beyond the imperative of reaching consensus, comes from the practices of design that are borne out of the agonistic theory of democratic processes, as developed by the political theorist Chantal Mouffe, and exemplified in the work at the Malmö Living Lab.¹¹ These agonistic participatory design practices aim at *infrastructuring* agonistic public spaces through the practice of the design lab, which is a space where long-term relationships are nurtured, heterogeneous groups are formed, and time is allowed for open-ended explorations and experimentations that can (re)articulate the public issues at stake.

These more adversarial practices of participatory design seem to encourage the formation of a public, which is political, conflictual, and has an appetite for change, as marginal voices try to reclaim their vision of the public and social spaces against the dominant discourses.

Political theorist Chantal Mouffe, together with Ernesto Laclau, has developed the concept of agonism and agonistic democracy. From Mouffe's standpoint, conflict is ontological and constitutive of public space(s) and democracy, and the central task for politics is to provide institutions that can permit conflict in a way that moves away from *antagonistic* practices, and toward more *agonistic* ones—in which the opponents are not treated as enemies but as adversaries with whom discussion is required.¹²

10 See, e.g., Kevin Olson, "Participatory Parity and Democratic Justice," in *Adding Insult to Injury: Nancy Fraser Debates Her Critics* (London: Verso, 2008); John Gaventa, *Power and Powerlessness: Quiescence and Rebellion in an Appalachian Valley* (Chicago: Illinois Press, 1980); and Sonia Ospina, Jennifer Dodge, Bethany Godsoe, Joan Minieri, Salvador Reza, and Ellen Schall, "From Consent to Mutual Inquiry: Balancing Democracy and Authority," *Action Research* 2, no. 1 (March 2004): 47–69.

11 See, e.g., Erling Björgvinsson, Pelle Ehn, and Per-Anders Hillgren "Agonistic Participatory Design: Working with Marginalised Social Movements," *CoDesign: International Journal of CoCreation in Design and the Arts* 8, no. 2-3 (2012): 127–44.

12 Chantal Mouffe, *Agonistics: Thinking the World Politically* (London: Verso, 2013).

The practice of agonistic design is not without its limitations. Although it offers opportunities for action based on engagement with institutions, rather than on withdrawal, how (and whether) these forms of design motivate action is still not clear. These forms also fail to provide an explanation for why the changes they are seeking to instigate are not happening and why marginalized groups, more than others, struggle to articulate their visions and alternatives. In fact, although the ontological construction of conflict might help us to better understand why people act, but it leaves us completely uninformed about *how* people are motivated to act—and especially *why*, within some circumstances, they do not act at all.

I next introduce two different theoretical approaches that might provide design with new lenses and ideas to promote participation that leads to change: (1) a phenomenological approach to participation, and (2) the role of affect in the political sphere. I then introduce an example from my own practice to illustrate how these two approaches are influencing my design work.

Social Weightlessness: A Phenomenological Approach to Participation

Drawing on Bourdieu, Lois McNay in *The Misguided Search for the Political* advances a fierce reproach of radical political theories (including that of Mouffe) and critiques what she terms “social weightless” thinking.¹³ The accusation is that these political theorists have recently pulled away from the social sciences and established themselves as a separate form of inquiry that aims at envisioning new ideal political systems, while failing to attend to crucial features of social reality, and particularly to the lived experience of inequality.

In moving away from the lived experience of “social suffering,” in assuming agency, and in demanding that radical action come from “below,” these political theories and theorists show a certain obliviousness to the everyday political reality of *inaction*. Hence, they are incapable of articulating a valid analysis and alternative measures for intervention. In fact, when applied in the practice of political movements, groups, and parties, these theories demonstrate the fallacy on which they are based;¹⁴ what they theorize does not happen, and the people they assume would act (because they do most fully embody the reasons for doing it) do not do so.

To overcome the tendencies toward “social weightlessness” in design, as McNay suggests in the realm of radical policies, we should re-establish a link between suffering and power, as a way of politicizing the former, where suffering is represented (by design) not as a general existential type of experience but as a social and political one.

13 Lois McNay, *The Misguided Search for the Political* (Cambridge: Polity, 2014).

14 Podemos, Siryza, and more recently Mélenchon, in the French elections, have all taken inspiration from Chantal Mouffe’s theory on agonistic democracy.

The Role of Enjoyment and Affective Politics

Since my first “encounter” with design, I recognized the practice of design as an inquiry that could critically engage with open and contested societal issues.¹⁵ What I found particularly relevant in design—in coming from a background of activism and radical social work—was not just its capacity to generate conflict or challenge the status quo, but also its generative attitude that seems to project it forward, engaging with the lived experiences of those who are marginalized, with the aim of making them visible and mobilizing them.

Mouffe’s theory involves a second strand that has been overlooked in its translation to design: the role of *passion*. By publicly engaging with their desires and fantasies and their pluralistic intimate passions, people become engaged and passionate about politics, says Mouffe. Instead of trying to understand conflicts by looking only at interests and rational discourses, Mouffe emphasizes “the affective nature of political engagement” as a more subtle way of understanding dissent. This role of *affect* in radical politics is itself worth more attention in design—namely, in respect to the interplay between enjoyment, meaning making, and resource mobilization. In fact, social and political issues frequently have a personal and private dimension, and in this dimension of the personal and private, meanings are created and contested and the collective imagination can be mobilized.

But Mouffe’s interesting excursion into the role of the emotional dimension of political life doesn’t explain much about how passions are linked to mobilization, how enjoyment (which Mouffe sees as a way of mobilizing passion) might be channeled, or what must be done to avoid the risk that passions end up legitimizing social inequality.

Exclusion and Inclusion in the Design Practice for Mental Health

To better illustrate how I try to use these two theoretical lenses in practical terms, I describe my practice of design in the mental health field. Doing so brings together some of the key themes that have been consistent throughout my work: the importance of engaging with the lived experience of those who are marginalized; the role of design in the complex dynamics of inclusion and exclusion, as a practice that can address issues of visibility and invisibility; and the matters of power and agency in the framework of design practice.

15 Carl DiSalvo, *Adversarial Design* (Cambridge, MA: MIT Press, 2012).

The participation of people who have a lived experience of mental health in the public space has a long and proud history. It is mainly linked to the tradition of service users movements and, specifically for mental health, the so-called “survivors movement.”¹⁶ Service users participation has historically taken three distinct forms: (1) *user movements*, borne out of collective action, and independent from any invitation or encouragement by public officials or other organizations; (2) *users involvement in services*, which can be described as consumerist (i.e., when the intention is to improve service efficacy and users satisfaction) or democratic (i.e., when the final aim is to enable people to have more control over the issues that affect their lives); and (3) *users involvement in research*, as a way of collectivizing knowledge production.¹⁷ In my design practice, I have combined these three layers to amplify their cumulative effect, starting from *user involvement in research*, and to build a ladder that could move participation up toward a user movement shaped by collective action.

In 2012, I started working with a mental health organization to build on their diffuse design capabilities,¹⁸ and to embed design practice and methods alongside their more traditional practices of service users engagement and advocacy and campaigning for social justice. The program aimed somehow at *decentralizing* the role and the agency of designers in the design process and at allowing non-designers, with the right support and resources, to reclaim the space of problem framing, issues formation, sense-making, and creativity. With this intervention, my goal was to reframe the role of expertise within knowledge production, and while not devaluing expertise itself, to confront expert and trained designers as a source of power and unchallenged authority. In my four years of working with this organization, I have set up a program that helps non-designers to use the design process and, even more importantly, that supports both people with lived experience of mental health and front-line staff to use design tools and techniques to carry out research and to gather insights.

The capacity to do research, should sit alongside other human fundamental rights as a capacity that has a huge democratic potential, says Appadurai.¹⁹ For those who have the means and the wish to do so, research gives them the tools to distinguish knowledge from fiction or propaganda, and cultivates alternative sources of knowledge production that challenge the dominant voices and visions and that make a creative use of those voices coming from positions of marginality.

16 Brenda Rush, “Mental Health Service User Involvement in England: Lessons from History,” *Journal of Psychiatric and Mental Health Nursing* 11 (2004): 313–18; and National Survivors Users Network (NSUN), *The Language of Mental Wellbeing* (National Involvement Partnership 2014), <http://www.nsun.org.uk/assets/downloadableFiles/4Pi-LANGUAGEOFMENTALWELLBEING.V42.pdf> (accessed March 2015).

17 Marian Barnes and Phil Cotterell, *Critical Perspectives on User Involvement* (Bristol: Policy Press, 2012).

18 Ezio Manzini, *Design, When Everybody Designs: An Introduction to Design for Social Innovation* (Cambridge, MA: MIT Press, 2015).

19 Arjun Appadurai, *The Future as Cultural Fact: Essays on the Global Condition* (London: Verso Books, 2013): 269.

In my practice I developed, together with colleagues, a design research training program, with the focus of providing people with lived experience of poor mental health with the design tools and skills to carry out their own design research. These design co-researchers are not dissimilar from those who, in anthropology, have been called “para-ethnographers.”²⁰ As such, they are not informants or just sources of raw data; instead, they become the producers of new knowledge and subjects who are able to theorize.

The “Thick” Description of Design Research

Design research lends itself very well to allowing non-trained designers to do the analysis and to disseminate the findings in ways that are accessible. In more traditional anthropological research—in fact, even when a para-ethnographic approach is used—the analysis and the task of providing the “thick”²¹ description that is proper to anthropological work rest with the ethnographer. (Note the absence of *para* here.) What could be described as the “thick” description of design research is, in my practice, the attempt to give access to the phase of interpretation and sense-making to non-trained researchers, allowing them to be involved in analyzing, producing meaning, and disseminating it. We have developed an “Insights Report” template to allow all co-researchers to contribute and to tell their stories using personas, quotes, and resources that help them to present and analyze the findings at glance. By taking ownership of accessible design research and tools, people with lived experiences have had the means to publicly affirm their “outsiders” ways of seeing, which draw on personal and cultural biographies as significant sources of knowledge.

Issues of exclusion and inclusion can (and should) be addressed from the research phase of the design process. For example, people with mental health issues can move from being the *object* to being the *subject* of research. Their personal stories can count as knowledge and provide valuable insights that allow the design work to progress.

This process of opening up design research to co-researchers with mental health issues is different from an agonistic approach in that it doesn’t assume the appetite for action and for challenging the role of the medical expertise among people with lived experience is already there. (This assumption is clear in the ontological model.) Instead, it focuses on *stimulating* that appetite

20 “Para-ethnography” is a term that emerged during conversations between George E. Marcus and Douglas Holmes in the late 1990s. It refers to the idea that the anthropological inquiry becomes a collaborative act when other counterparts, who are not trained anthropologists, collaborate in the ethnographic endeavor.

21 In anthropology Clifford Geertz popularized the concept of “thick description,” picking it up from Gilbert Ryle and applying it to the intellectual effort of researchers, who provide a detailed description as a result of ethnography and an interpretation of the meaning behind visible behaviors and facts that can be observed. See Clifford Geertz, “Thick Description: Toward an Interpretive Theory of Culture” in *The Interpretation of Cultures: Selected Essays* (New York: Basic Books, 1973), 3–30.

by allowing people to share and reflect on their stories, distinguishing knowledge from propaganda, and making visible the fact that every narrative is predicated on the exclusion of other possible narratives. The approach allows us to see that things can always be otherwise and that other models could (or should) have the same dignity and space to be affirmed politically.

But how does this changed perspective apply to mental health specifically? And how could it be used with other groups and in other contexts? These questions can be answered on two levels. On the pragmatic one, various conditions and processes must be put in place to ensure a respectful and meaningful engagement for people with mental health issues in collaborative design practices. In my case, working within a mental health organization, it meant drawing on their expertise and their existing engagement policies, which carefully outline the steps for recruiting, engaging, and supporting participants who have mental health issues.²²

Getting these practical steps right is almost (or should be) a given in a good participatory exercise; nevertheless, they still are far from ensuring parity in participation. Thus, the need for the second level, which is ideological and political, comes in. What makes my practice of design specific to mental health is exactly that it comes from *within* and builds on the ideological framework of the users' movement tradition.

Building on this tradition has changed my perspective and thus my practice in several ways. First, the idea to directly frame the question of mental health as political from the start comes from the work of the activists who have mental health conditions and build on their own personal experiences of using mental health services. Second, giving service users access to design research tools and techniques follows the long tradition of the "survivor's movement," in which story-telling produces the users' own knowledge and accounts.²³ Third, the idea of building a link between the "social dimension of suffering" and affective politics comes from the movement's perception that social and political issues have a personal and private dimension that needs to be explored, too.

Would this specific perspective translate well to other groups—for instance, within health or social care intervention? The answer, based on my experience, is yes, but the ideological framework must be adapted and different steps taken to reflect the different subjects. In my experience, this adaptation seems to work better when the groups share some key characteristics with the field of mental health, including its power dynamics, social awareness, levels of activism, and mobilization.

22 The organization had in fact developed an internal "Engagement Policy" that identified different levels of engagement for different purposes and offered recommendations on, for example, the choice of the venue, how to draft the invitation, and how to provide payment for the expenses and for people's time (for the people invited and for their carers, if needed).

23 A Survivor History Group, run by mental health service users and survivors, documents the history of the movement through a collective archiving and story-telling work. It draws also on the memories of those who took part in the events. See <http://studymore.org.uk/mpu.htm>.

The Peer-Support Employment Project

In a recent project to explore how we might transform employment and back-to-work support for people with mental health problems, we trained five researchers—both staff and people with lived experience.²⁴ Together, these co-researchers identified the areas of investigation; recruited the people to interview; and carried out some basic ethnographic research to come up with initial findings and themes. What these co-researchers produced, after the research phase was terminated, was an honest, in-depth, and rich description of the experiences of many who had gone through the journey: from being employed, to becoming unwell (sometime because of pressure at work), to losing their job and having to look for a new employment, while dealing with a mental health condition and the stigma attached to it. The richness of the stories came not just from good ethnographic research, but from the added value provided by an autoethnographic approach.²⁵ Half of the researchers had a lived experience of poor mental health; they potentially experienced similar feelings and episodes as they disclosed their mental health status to their managers, or faced similar discrimination as a result, or felt similarly out of place in work-based environments and relationships. Because of these shared experiences, the researchers could feel close to the stories shared by the people they interviewed: the stories were authentic to them and deeply meaningful and moving.

The next step was to move the issues from a personal perspective to a political one. This step is the most delicate because the choice to assume a political stance depends deeply on people's lives and their experience of marginalization, on their authority (or lack of thereof), and on their desire to do things differently, possibly kindled by a long-term commitment in activism, advocating for better conditions for services and support. Different people react differently at this point of transition, and this variability is inevitable.

In the employment project, the team and I used a series of design workshops, to which only people with lived experience and staff were invited, to build the key concepts and identify the themes that would be used to frame our interventions in the future. In the workshops, we made visible the experience and the journey of those who had experienced mental health issues and who were trying to get back into employment. We highlighted the commonalities of these stories and developed a shared sense of awareness and alternative narratives that countered the stereotype of “the scrounger”—the predominant metaphor in official discourses around economic benefits, mental health, and

24 The issue of work and mental health has been at the top of the UK agenda around employment policies for a long time. There has been increasing recognition that more needs to be done to help people to stay well at work, to avoid people falling out of work because of mental health problems, and to support people who are out of work because of their mental health to move closer to employment. You can read more in the Mind report, “We’ve Got Work to Do” (London: 2014) https://www.mind.org.uk/media/1690126/weve_got_work_to_do.pdf (accessed December 2014).

25 Autoethnography is an approach to research that describes and analyzes personal experience to understand the cultural experience of the subject. This approach treats research as socially just, and socially conscious and it questions the right of researchers to represent others in our research. See Stacy Holman Jones, “Autoethnography: Making the Personal Political,” in *Handbook of Qualitative Research*, ed. Norman K. Denzin and Yvonna S. Lincoln (Thousand Oaks, CA: Sage, 2005), 763–91.

employment.²⁶ We framed the issue not just as a story of unemployment, but as a common experience of discrimination, neglect, and exclusion that contributed to build a sense of the “we” in a political way.

Why Don't People Get Political?

Opening up the research phase to people who have had or do currently have a mental health condition and giving them the training, the tools, and the space to explore their own and others' stories can be a very powerful way to include marginalized groups in the next phase of the design process. However, research on its own, the production of alternative knowledge from alternative sources, and the exposure of the non-visible are not always sufficient to achieve a shift and to move people toward collective action. Obstacles to participation do not take the form of easily identifiable external barriers, and the long exposure to marginalization could prevent people from constructing their problems as political in the first place. Even when they do so, as in the example provided, a corrective political action is far from assured.

What are the main issues and barriers I have encountered, and the possible solutions? The first one is the question of *time*. I see no quick fix or solution to the issues of exclusion in design, as I have framed them. To overcome the *paradox of participation*, we need to build people's confidence and create connections, through their stories and other people's stories, and the telling and connecting requires time. For this reason, in some cases, I have spent years working intensively with participants, not just for the purpose of ethnographic research and workshops, but to fully *hang out with* and take the side of these people—to share their burdens; to learn about their lives, their families, and friends; and to create a connection on a personal level.

The second issue is the question of *progression*. The journey toward inclusion of marginalized subjects into design work goes through progressive steps of engagement—from user engagement in research, to democratic forms of user involvement, to collective action. Again, time is fundamental, as is our awareness of different ways to design progression *within* our practice of design. For instance, we might deliberately include moments of reflection for all the participants involved; or make the progression visible and offer multiple options by which people can become involved, at their pace and in their way. And perhaps we need to leave all the design tools and resources with these people, so that they might use them again in the future to do the design themselves.

26 With the financial crisis and the policies of the Conservative Governments in the UK from 2010, the perception around people with mental health who cannot work has changed as public opinion more and more feels that these people are “scroungers” that are exploiting the system of support.

The third question involves the concept of *recognition*, as a fundamental condition to allow for parity of participation.²⁷ This complex concept requires us to acknowledge that acting for the recognition of marginalized groups means developing a deep understanding of the dynamics of exclusion and inclusion; that what people might need to participate is different at different times; and that the production of “difference” can be both a privilege and a trap. People don’t always need to be included and recognized in the same way in every context: Sometimes they need to have their distinctiveness and difference highlighted, and sometimes they need the opposite. At other times, for instance, highlighting the differences in the dominant or advantaged groups might be useful—to point to their ways of being different too, which are often just ignored or taken for granted.

Final Reflections on Design Theory

I started this article by highlighting the overly optimistic tone of many publications and case studies that oversimplify the role of design in public and community organizations and that present a palatable version of design that *designs out* conflict and dissent and magically allows for true participation to happen. Maybe as a reaction (and a provocation), I have tried to complexify the role of design in ensuring true participation and also to present the idea that participation is a paradox in itself—something we strive for but can never achieve.

I identified the limits of agonistic models as theorized by Chantal Mouffe, as well as two possible alternatives with which I’ve experimented in my practice: 1) re-appropriating identities by constructing the experiences of suffering and exclusion as a political category, and 2) encouraging and nurturing the passional side of politics and conflict by publicly affirming outsiders’ ways of seeing, which are drawn on personal and cultural biographies.

Through this article, I have tried to exemplify two key trends and developments in the practice of design to encourage their practice more widely: an enhanced sensibility toward issues of power and agency in design and a deep questioning of the roles of design and designers. Questions of ownership and power are long overdue in the more optimistic accounts of collaborative design as ethical and good in its own right. This uncritical stance is due partly to a lack of critical understanding. According to Donetto et al., “the different types and facets of power operating within a specific setting, their configurations and their possible effects, the discourses of service user empowerment and democratization of service provision risk being deployed simplistically, thereby obfuscating more subtle forms of oppression and

27 Nancy Fraser and Axel Honneth, *Redistribution or Recognition? A Political-Philosophical Exchange* (London: Verso, 2003).

social exclusion.”²⁸ Other scholars and practitioners also are developing interesting insights around questions of positionality and the identity of designers, exploring the role of critical thinking for improving design practice, and developing a better understanding of the role of power and authority in the more mixed assemblages that constitute design agency.²⁹

The second strand of contemporary design research reflected in this article questions the role and identity of, and the need for, design and designers as we know them. During a recent symposium in Malmö, Clive Dilnot mentioned the risk that design might “dissolve,” as when designers are working with other professionals and expanding into other disciplines, fields, and practice (e.g., design in politics).³⁰ This risk of design’s disappearing is a risk that has to be faced and taken. Similarly, DiSalvo recently reflected on the risk, suggesting that a more engaged practice of design (i.e., one where the designer works in-house for a single client for years, maybe even decades) is an interesting model that could expand the influence of design to complex societal challenges. However, it also inevitably raises issues related to a less-defined design identity, which perhaps blends more with other practices and, through long exposure to a different professional culture, gets to question and maybe to change its nature into a more hybrid one.³¹

I can borrow from Arturo Escobar and his definition of “autonomous design” to more clearly, and I think more beautifully, describe where I see design going:

(...) autonomous design can be said to stem from the following presuppositions:

1. Every community practices the design of itself... [F]or most of history communities have practiced a sort of “natural design” independent from expert knowledge....
2. Hence, every design activity must start with how people themselves understand their reality. In philosophical terms, this means fully accepting the view that people are practitioners of their own knowledge....
3. ...As designers (say, with a community or group of people), we may become “co-researchers” with “the people,” but it is the community that investigates its own reality.³²

In this framework, solutions grow from places and situated identities, and cultivating design intelligence becomes a key aspect of giving to everyone the tools and resources they need to create a public space, initiating discussions about issues that affect them directly, as well as issues that affect the wider society.

28 Sara Donetto, Paola Pierri, Vicki Tsianakas, Glenn Robert “Experience-Based Co-Design and Healthcare Improvement: Realizing Participatory Design in the Public Sector,” *The Design Journal* 18 (2015): 227–48.

29 See, e.g., Mahmoud Keshavarz and Ramia Maze, “Design and Dissensus: Framing and Staging Participation in Design Research,” *Design Philosophy Papers* 11 (2013): 7–29; and Simon Bowen, “Critical Theory and Participatory Design,” (paper presentation, Conference on Human Factors in Computing Systems, Atlanta, GA, (April 10–15, 2010); and Cameron Tonkinwise, “Design for Transitions – from and to What?” *Design Philosophy Papers* 13, no. 1 (2015): 85–92.

30 Clive Dilnot, closing remarks of the Intersectional Perspectives in Design, Politics & Power Symposium, Malmö, Sweden, November 14–15, 2016.

31 Carl DiSalvo, “Three Reflections on the Transition Design Symposium Provocations,” *Design Philosophy Papers* 13 (2015): 51–55.

32 Arturo Escobar, “Notes on the Ontology of Design,” 46, http://sawyerseminar.ucdavis.edu/files/2012/12/ESCOBAR_Notes-on-the-Ontology-of-Design-Parts-I-II_-III.pdf (accessed June 2016).