Intersectional Perspectives on Design, Politics and Power
School of Arts and Communication, Malmö University
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Why people do not rebel?

Issues of self-marginalisation in design for mental health

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Abstract

In this paper, I will take the opportunity of the Symposium organised by the Decolonising Design Group to explore what does applying a lens on intersectionality do to my practice and my research around issues of participation and agency in design. I will start by introducing my research interest and my current practice and reflecting on the issue of participation in design. I will then apply an intersectional lens to my thinking and my practice, working with people with mental health conditions, trying to reframe the issue of inclusion/exclusion through the work of Patricia Hill Collins and her conceptualisation of the 'outsider within'. I will conclude my paper by reflecting on what is still missing and where the failures and frustrations are in my work in mental health at the moment, and present the areas that I am currently exploring as possible ways forward to improve the impact that my practice can have, by looking at how to politically link social suffering and power.

1. INTRODUCTION

In this paper I will reflect on what an approach based on intersectional theory does to my practice as an activist, who is using collaborative design approaches in the field of mental health services. The reason why I am using an intersectionality lens in my work is to unpack the complex question of participation, by looking into issues of identity and oppression, and how these end up influencing and affecting the way people act, or sometimes they ways and the reasons they don't, within participatory encounters. Before I start defining what intersectionality is and how I came to address issues of intersectionality in my work, I would like to set the context of my research and my practice, and also introduce my thinking, which I have more broadly presented elsewhere, around the question of participation.[1]

My research interest originates within my professional involvement in social projects, where I have been introducing design approaches and techniques as ways to harness people's creativity and knowledge, towards the identification and the practice of new models of citizens' participation. The question of participation is quite a central thread in my work, as this is something I have been concerned with for many years through my practice first, and my research more recently.

Based on my experience in the UK context, discourses of participation in design often fail to represent the ethical complexities of working in a collaborative way, and a lack of critical perspectives on participation often translate in a poor understanding of power dynamics and contribute to the risk of *romanticising participation* for the sake of participation in itself (Collins and Cook in Sangiorgi et al 2014), by assuming that participatory forms of design are in and of themselves an ethical act in the quest for ethical outcomes.

Especially in the context where I operate, which is the field of social and health services in the UK, this is not always the case, as a certain tradition of 'service users engagement' has taken over, where individualist forms of involvement are privileged over more relational and political ones. Cribb and Gewirtz, for instance, describe this issue through the idea of a 'compliant participant'[2] - from whom certain types of participation are encouraged and requested; while others, like for instance people getting together to protest against the quality of care they receive or the cuts to public services, are non encouraged or actively discouraged.

As these authors suggest, then, is not participation tout-court what is envisaged but a well-defined type of participation, which responds to specific moral imperatives and raises specific normative expectations. If

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participants do not align, service users are at risk of being constructed as either irresponsible, or disengaged or somehow wrongly engaged.

So what are we really talking about when we are talking about participation? Who is constructing this idea of participation? And what are the expectations on both sides? What would be allowed and encouraged in a participatory design encounter, and what would not be allowed?

2. PARTICIPATION AND THE INTERLOCKING NATURE OF OPPRESSION

Many scholars in political science argue that participation is actually a sort of paradox in itself. Something that we can strive for but never achieve, in a context of power unbalance and within current deliberative models of public space. As we do not operate within a system of direct democracy, we end up using forms of participatory design as surrogates to perpetuate the illusions that we could replace true participation.

The more we try to assume *equal* agency and allow for spaces, platforms and tools for everyone to *equally* participate, the more we are actually reproducing the structures of imbalanced power and unequal capacity to act.

This is mainly due, as I will try to articulate in this paper, to the *internalised domination* that makes marginalisation not simply an explicit violation of equality, but something more subtle that deprives individuals themselves of the capacity to demand equality in the first place. Some obstacles to participation, for instance, do not take the form of easily identifiable external barriers but they present themselves in more sophisticated and unexpected behaviours. This internalised domination, in fact, deprives individuals themselves of the capacity to demand inclusion, it may prevent them from constructing their problems as political, and corrode their willingness to participate in corrective political actions.

This is a fairly well documented phenomenon if we look at the mental health field. Together activists, survivors, as well as scholars, have contributed to describe and make visible the *"self-stigma"*[3] that people with a mental health diagnosis may internalise and that could lead to lowered self-esteem.

Drawing on Meyer's[4] study on mental health in LGB groups (lesbian, gay, bisexual), Kristina Hallett

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[3] Hallett, K. 2015, Intersectionality and Serious Mental Illness – A Case Study and Recommendations for Practice, Women &Therapy, 38:156-174

[4] Meyer, H. I., Prejudice, Social Stress, and Mental Health in Lesbian, Gay, and Bisexual Populations: Conceptual Issues and Research Evidence, in Psychological Bullettin 2003 129(5): 674–697.

reminds us that the greater one's perceived stigma (or *self stigma*), the greater the expectations to receive negative regard from members of the 'dominant' group. *Stigma consciousness*,[5] as this has been defined, is in fact the realistic reflection of the lived experience of discrimination for people with mental health (as well as from other minority groups).

This *internalised* negative attitude, fear, sense of disconnect is what I have witnessed many times in my practice, taking the forms of a struggle to speak up (or sometimes simply to speak) in public events, like for instance a design workshop; or the difficulty of drawing on the knowledge that comes from one's own experience of living with a mental health condition or using mental health services; or also the struggle to imagine and articulate a vision for how things could be different and what good would look like, beyond what is available at the moment. As Appadurai very well describes, what I have witnessed is the lack of the *capacity to aspire*, that social and cultural capacity to plan, hope, desire, and achieve socially valuable goals.[6]

And this is how the concept of intersectionality comes into my practice, as it makes me reflect on the interlocking nature of oppression, which means seeing oppression as a very sophisticated phenomenon, which is not at all banal but builds on multiple individuals dimensions of people's social lives and reinforce each other and connect to each other in complex and unexpected ways. This means in practice that I try to not just look at the *dimensions* of oppression and exclusion (whether these are based on gender, class or mental health), but trying to capture the *connections* and the *interplays* between these various dimensions, as they happen concurrently. And this means, for instance, realising *'the potential for an individual to experience both advantage and disadvantage simultaneously in regard to various social identities.'* (Hallett 2015); but also paying more attention in my research at the ways in which people identify themselves and how different identities take different meanings in their lives, and which ones are more important, when and in which context.

3. INTERSECTIONALITY AND MY PRACTICE IN MENTAL HEALTH

The notion of intersectionality is not new to the field of mental health at all, but a more self-aware approach to intersectionality is needed in the mental health system to make visible all the layers of identity, discriminations, and power structures that interact in the mental health itself. We shouldn't forget, for instance, that within medical models of mental health it is the culturally dominant group that get to define what the healthy, appropriate ways to conduct oneself are, and do so in accordance with their own norms and practices.

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[5] Again this term is referenced in the paper from Kristina Hallet where she is drawing on the work Elizabeth C. Pinel.

[6] Appadurai, A., 2013, The Future as cultural fact: essays on the global condition. London: New York: Verso Books.

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An interesting work that explores how the question of intersectionality links with health (care) research and, specifically mental health, is the work from Van Mens-Verhulst and Radtke[7] on this topic. In resisting a reductionist approach and by including the individual and all her different identities and the interplays between them, intersectionality, they posit, has much to offer to mental health care research, as practitioners and researchers in this field struggle to grasp the complexity of hybrid positions and identities associated with diversity.

Looking specifically at the mental health field, they have observed at least six cases, where the lack of understanding and consideration of questions of intersectionality, has consequences on the framing of the identity, the diagnosis and the treatment of the person . I am going to quote from their paper what these six cases are:

1. *"inappropriately ascribing characteristics associated with a social group to individual group members, e.g., assuming that the depression of an elderly immigrant woman must be due to homesickness;*

2. *turning observed differences into new stereotypes, such as `the depressive older lesbian';*

3. *transforming descriptive categories into normative ones and pathologising those who depart from that norm - usually men, native speakers and healthy adults are depicted as the healthy standards with women, foreigners and the elderly seen as deficient and unhealthy or foolish;*

4. *blindness for within-group differences, resulting in a homogenized image of men and women clients, irrespective of their ethnicity, sexual preference, marital status, age, education and income;*

5. *overestimating differences and underestimating similarities between groups, such as between non-western and western women (although the health care system is mainly founded upon assumed universality of biological, psychological, and social processes that are related to health); and*

6. *essentialising differences by postulating a biological origin and claiming that they cannot be modified, e.g., presenting sex differences in depression as the inevitable consequence of a difference in hormone levels."[8]*

I find this list is really helpful and that very well summarises how an approach based on intersectionality could improve mental health care and the services that people receive. And I believe this list could also be applied to other groups and other conditions or identity traits, as these dynamics are unfortunately not limited to the field of mental health.

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[7] van Mens-Verhulst, J. and Radtke, L. 2008. Intersectionality and Mental Health: A Case Study, ITS Traveling Retrieved from http://www.vanmens.info/verhulst/en/wp-content/INTERSECTIONALITY%20AND%20MENTAL%20HEALTH2.pdf on October 2015

[8] In their paper van Mens-Verhuls and Radtke also illustrate the perverse implications of when these cases apply on the quality of care that people receive: the risk of the therapist putting patients into stereotypes while ignoring their self- understanding of their condition, the risk of being pathologised if they do not fit with the models and finally the risk of of treatments failing to acknowledge the important of the social context.

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Before I move on to describe how I am using the lens of intersectionality in my design practice, which is about embedding design in the mental health setting, I think it would be important to say a bit more about how I frame mental health and what kind of interventions I focus on my practice. Following from certain mental health users' movements, I frame mental health within the so called 'social model' of mental health, which is opposed to the medicalised individual models of 'mental illness' that continue to predominate in the policy, practice and analysis of 'madness' and mental distress in the UK.[9] This idea of the 'social model' comes originally from the disabled people's movement, which was successful in shifting the blame and responsibility from the individual to the society, by affirming 'disability' as a discriminatory and oppressive response to people seen as having an impairment, rather than a characteristic attached to the individual. This means that all the services, campaigns and interventions that I refer to in my practice are developed within this model and the tradition of community based mental health services, which includes actions as peer-support, arts-based interventions, talking therapies, and other non-medical approaches.

4. INTERSECTIONALITY IN MY DESIGN PRACTICE

Since 2013 I have been working in a national mental health organisation in the UK to develop a programme that: helps non-designers to use design techniques to create new services or to improve existing ones; but more importantly a programme that supports people with lived experience of mental health and front-line staff to carry on research and gather insights to provide alternative ways of developing knowledge and telling their own stories, that draw on their experience of using the mental health system.

The rationale behind my practice draws, among others, on the reflections from Patricia Hill Collins[10] around the sociological significance of black female feminist thoughts. Similar to what Collins describes in fact my practice is about using design as a way of making a creative use of 'marginal voices' and positions of marginality, by making visible the knowledge, the expertise, the skills, the passions of those who are rarely visible (e.g. volunteers, people with lived experience, people using mental health services, front-line staff). As 'outsiders' living on the edge of society, in fact, people with mental health issues develop their ways of seeing reality and framing their conditions and the possible ways to improve their lives. With my design practice I build on the 'diffused' design capabilities[11] of people with lived experience of mental health and try to grow these, by allowing people to develop ownership of accessible design research and creative tools. In this way, using Collins language around the idea of the *Outsider Within*, I am encouraging and publicly

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[9] Beresford, P; Nettle, M. and Perring, R., *Towards a social model of madness and distress? Exploring what service users say*, (London: Joseph Rowentree Foundation, 2010)

[10] Hill Collins, P. 1986. Learning from the Outsider Within: The Sociological Significance of Black Feminist Thought, Social Problems, Vol. 33, No. 6, Special Theory Issue, pp. S14-S32

[11] See Ezio Manzini vision around 'diffused design capabilities' in "Design when everybody designs"

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affirming 'outsiders' ways of seeing, which are drawn on personal and cultural biographies of people with lived experience of mental health as significant sources of knowledge.

In her work Collins outlines 3 themes that I have tried to tie and translate into my design practice. First Collins talks about the *importance of self-definition and self-valuation*, which is something that I have been exploring in my workshops by inviting people with mental health to play the active role of designers in order to develop characters and stories about mental health, that can replace externally derived categories and frame these new narratives with self-owned ones. Second, she reiterates the importance of recognising the *interlocking nature of oppression*. This is perhaps, as I have briefly articulated above, the most important and, at the same time, the most difficult one to translate effectively into the design practice. This is partly due to the fact that a design project is not long enough to do anything that could resemble a process of awareness raising and a serious and honest reflection about different identities and theie interplay and how it feels to be at the 'intersection' of these identities and how is this different from just living in the space of one of them. This is an area where more work and time would be needed and where I am currently focusing my attention to develop more effective techniques and tools that can operate in the longer-term. Finally, in her paper Collins also talks about the *importance of the lived experience point of view*, and this is where design can be really powerful, as it encourages a perspective and a viewpoint that are relocated to the subjective level. In my workshop this is activated by allowing people with mental health conditions and staff to collect and tell other's people stories, through design research, and reflect differently on their own lived experience.

Trying to summarise then, I would say that what intersectionality does to my design practice is to confront me with the difficult task of critically taking into account the complex systems of oppression, as these could prevent marginalised people from acting in their own interest, or sometimes just from acting full stop. The idea of intersectionality then provides me with an additional layer to explain how dynamics of (self-)exclusion and inclusion happen in different ways and according to different identity traits. It also reminds me that privilege as well could similarly manifest itself in multifaceted forms and ultimately how that privilege (or lack thereof), informs for instance my action, and my design practice.[12]

5. CONCLUSION

In this paper I have tried to re-tell the story of my research and practice through the language, the sensibility and the lenses that an approach based on intersectionality provides me.

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[12] Rizvi, U.Z., Decolonization as Care, Part 15 of 15 of the Decolonizing Anthropology series, http://savageminds.org/2016/09/19/decolonization-as-care/, retrieved from the web on 21st September, 2016

I would now like to use the space of the Conclusions to briefly reflect on what is still missing, how is my practice failing and what alternative approaches I am currently exploring.

As I have hopefully illustrated in my paper and in describing my work, the main frustration and my main failure in my practice comes from the incapacity, so far of motivating people's agency through design, and this I think is mainly due to the way I have been constructing the notion of conflict, by drawing on agonistic models of participation.[13] These in fact, while being really helpful in making me understanding why people rebel, left me completely clueless on how people are *motivated* to rebel and, especially, why they don't. The issue that I have with these models is then thatm, as they unproblematically assume agency, they don't know what to do when people, even if given the opportunity, 'decide' to not act!

In the attempt to overcome and investigate these aspects, I have recently found myself, in my quest for alternative theoretical approaches and analysis, looking into different directions, away from agonistic models and towards rediscovering a phenomenological approach to radical democracy.[14]

My work towards embedding this new approach into my practice has only just started but there are a few thoughts that I think can be shared at this stage, regarding:

• The *quality* of engagement – which manifests for me in the need as the 'facilitator designer' to take part and partake, which means being involved with the work I do and the people I work with on a very personal and even intimate level, by connecting and reflecting more on my identity and how I position myself in the context of designing;

• The *quantity* of engagement: which makes me rethink the timeframe of design practice beyond the timeframe of the project. Issues of interlocking oppression and internalised stigma and marginalisation, in fact, cannot be addressed in the space of a workshop. A longer time and engagement is needed, which could be months or even years long;

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[13] See Chantal Mouffe's agonistic model of democracy.

[14] Lois McNay is a Professor of Theory of Politics at Oxford University that has been writing about the limits of models of radical democracy. In her book 'The Misguided search for the political" she critics the rise of a vision of the political that has now developed only a tenuous connection with the lives of those on whose behalf it claims to speak and have become (borrowing the term from Bourdieu) "social weightless", which means that this form of political thinking is so far removed from the actual practices and dynamics of everyday life that its own analytical relevance and normative validity are thrown into questions. To overcome the tendencies to "*social weightlessness*", McNay suggests that radical democrats need to attend more to the social conditions that may be necessary to render their ideas of political action feasible. A more fruitful approach, McNay argues, would be one that establishes a link between suffering and power, as Bourdieu said, as a way of politicising the former, where suffering is not a general existential type of experience but a social one.

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• The *nature* of engagement: as design becomes more like a political practice, rather than an intervention, and designers act more like activists that stand up for the battles they care about and share a political passion and vision with the others involved.

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She studied Politics as Undergraduate, she has an MA in Community Development and she is currently doing her PhD at University of the Arts, London on design anthropology, exploring the role of design in future making and for social change.

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