UNDERGRADUATE HONORS PAPER

HOME IS FOR THE MAKING

Rethinking Home in a Participatory Action Based Workshop

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INTRODUCTION: WHY HOME?

Home is a word so loaded with identity and memory, aspiration and nostalgia, that to examine it closely is to, intentionally or not, implicate nearly every facet of a person's life. Home can be both a place of *dwelling* and an emotional sense of *belonging*. Individually owned land, typified by the suburban home space, domestic, private and privately owned, heteronormative, white, and familial is the ideal pursuit promoted and reinforced by the current socioeconomic, political and cultural context. The land and settings of this ideal are vaguely bucolic but the houses are generally dependent on costs externalized to the environment and marginalized peoples. Of course, many do not have access to this suburban house—the most recent subprime mortgage bubble underscored both how desired this "home" is, as well how it has been fundamentally commodified. The tragedy of this most recent financial crisis was both the gain and the sudden loss of those dream houses.

Many groups, including those living with mental illnesses, have been circumscribed by their lack of access to these homes, not only financially, but as *not-belonging* to the concept of home. The historical institutionalization of those with mental illness, compounded by an undermining suspicion of their ability to be self-aware, self-actualized, and safe people excludes them from the very definition of home as a place of security, privacy and identity formation. The policies that seek to redress these disparities, these exclusions, often offer up a version of home either as a consummate place of wellbeing or resign to simply offering shelter—as if walls and a bed were all it took to make a home. In offering simplified or un-critiqued "home" there is a risk of continuing to cover up and erase the experiences of those marginalized because of their mental illnesses and maintaining their exclusion from "home." Failing to consider a dissonant yearning for the ideal offered incompletely and inconsistently by policy or recognize altogether alternative

understandings of home that incorporate and embrace differences is a failure to self-reflect and advocate for places of inclusion. Why home and what does it mean? This is a question broadly relevant but the salience of home is accentuated by those traditionally excluded.

Home for those who live outside the normative notion of a private space may have complicated realities, may be endowed with a traumatic experience such as loss or abuse. It may be fragmented by displacement or the incorporation of the public. This paper argues that for advocates trying to close gaps in health and wellness for marginalized groups like people living with mental illness, it is essential to consider critiques of the very idea of home which policy extends.

However, I also argue that this critique is incomplete if it stops with the *experience* of exclusion. Part of this exclusion is inherent in the dynamics which license researchers and providers to generate or synthesize knowledge and demote the patient's and researched's participation in the process. A more complete critique must offer access to knowledge formation surrounding the understanding of home to people living with mental illness. It will both collect and amplify their voices surrounding the lived experience of home but also facilitate a self reflexive group process of reimagining "home" as a flexible space that embraces differences which may undermine dominant constructions of this space.

NURSING & HOME

Liaschenko's (1994) writing on home health and mental health nursing broke theoretical ground as she identified the ties nursing has to home spaces and essentially initiated an exploration of the geography of nursing. While her critique is not on the actual *meaning of home* it does highlight the ways in which institutions of healthcare infiltrate the home, carrying the "medical"

gaze" into a locus of identity and privacy for many patients. As spaces, hospitals are focused on curing and mitigating disease and these goals are the framework that defines all aspects of patient care and interaction (Liaschenko, 1996). Throughout history, nursing frequently serves this medical gaze, the nursing skill of assessment often acting as the eyes and ears of physicians. Liaschenko proposes that as the nursing profession gains autonomy in healthcare—nurses are increasingly able to implement the "nursing gaze"—patient centered care which ultimately distills to advocacy—assessing and incorporating patient experiences and values (Liaschenko, 1994, p. 23). She argues that Nightingale keenly understood that assessment carries with it the power of whomever it serves and whatever framework its beholder ascribes to.

"... it must never be lost sight of what observation is for. It is not for the sake of piling up miscellaneous information or curious facts, but for the sake of saving life and increasing health and comfort. The caution may seem useless, but it is quite surprising how many men (some women do it too) practically behave as if the scientific end were the only one in view, or as if the sick body were a reservoir for stowing medicines into and the surgical disease only a curious case the sufferer has made for the attendant's special information." (Nightingale, *Notes on Nursing*, as cited in Liaschenko, 1994, p. 24)

As early as the beginning of the modern nursing profession and the modern hospital, Nightingale had identified both the risk of reducing patients to an illness or disease as well as the nursing role in advocating for a more comprehensive understanding of a person. As home increasingly becomes the site of health care, Liaschenko introduces the geographical critique, prompting nurses to pay attention to the power and values inherent in place and space. What opportunities

and risks do providers, especially nurses, have when working in these traditionally "private" spaces?

"Home is different. Home care providers know that home is a place offering a wider view of the patient's life, disease, illness and suffering." (Liaschenko, 1996, p. 50).

Instead of institutionalizing patients in their home with the scrutiny and priorities of medical institutions, she argues nurses must work to advocate for their patients. However, she pushes the profession further, to consider if there are spaces and places that could deinstitutionalize nursing from a reductive, biomedical view inscribed in hospitals. Can nursing care be intentionally integrated into specific places in a way that can reinforce nursing perspective? How might nurses consider the voices of groups, such as those who have lived with a mental illness their entire life, with a fragmented experience of home, or for whom home never has been a place without medical institutions? In this case, might the nursing role be to foster and empower the person to cultivate an environment that offers resilience and agency as the basis of wellness? Liaschenko's understanding of both home and nursing upends traditional hierarchy and institutionalization of those with mental illnesses and the nursing profession in a way that parallels the work at the Farm at Penny Lane, and strikes a tone for the following participatory action based workshop.

GEOGRAPHIES OF HOME & HOUSING & MENTAL ILLNESS

A critique of home necessarily draws on interdisciplinary perspectives. As a historically excluded and controlled group, home for people with mental illness is bound to support services and efforts to control a group portrayed as "deviant." Home, housing, and care are deeply geographical in nature. Understanding their spatial distribution helps elucidate the ways home

has evolved for those living with mental illnesses. Michael Foucault's (1988) seminal work on the institutionalization of those with mental illness traces the rise of the asylum in which, historically, all matter of excluded groups had been interred, from those on the brink of death to the poor to those with mental illnesses. However, it is those with a mental illness that are the remainder interred in the asylum at the turn of the 21th century. Foucault's work scrutinizes the ways in which a dominant notion of propriety protects itself by circumscribing those with mental illnesses as deviant. This "deviance" is used as cause for legitimate internment and disenfranchisement. The genesis of the psychiatrist/patient duality is in these institutions. These roles carry persisted even after deinstitutionalization policies gained popularity in the mid-1900's (Foucault, 1988; Parr, 1999). The asylum geography of mental illnesses portrayed a landscape of large, centralized hospitals, on the urban outskirts or in inner cities (either way, often located away from a city's middle and upper class residents) where home, care and control of those with mental illness was provided (Wolch & Philo, 2000). However, even outside the asylum, the person with mental illness has been assigned to this role in which another, the psychiatrist or provider, holds the keys to one's knowledge (Parr, 1999). This is a powerful stigma that impacts the experiences and identities of those living with mental illness, whether or not they have ever been hospitalized.

Despite the unequal power dynamics, these asylums were the site of home for many people. Popularly portrayed as sites of abuse and neglect, they were simultaneously places where staff strived to create true *home* for those interred there (Anderson, 2003). Their closure has left a lasting, sometimes ghostly impression in the memories of those who lived and worked in them, as both home, occupation and identity (Parr, Philo, & Burns, 2003). Deinstitutionalization, paired

with "community integration" policies beginning the 1960's, 1 seemed to close this chapter in mental health geographies, leaving open the question as it had not existed before: if those with mental illnesses did not belong in an asylum where exactly would they, could they belong? Where was home? (Dear, 2000; Wolch & Philo, 2000; Yanos, 1997; Yanos, 2012).

Ushered in with the *Comprehensive Community Mental Health Centers Act* (1963), public policy and court decisions favoring "community integration" of those with psychiatric illnesses began to redefine "home" for those long-relegated to asylums (Hein & Scharer, 2015). Since the decentralization of the mental health system and the closure of large, state run psychiatric facilities, there has been a marked spike in disparities in health and housing. People diagnosed with mental illnesses, such as schizophrenia or bipolar disorder, are more likely to be diagnosed with other chronic illnesses, such as heart disease, and more likely to die earlier than a peer with no diagnosed mental illness (Cunningham & Peters, 2013). More subtlety, this stress of living in transitional spaces or housing that don't promote independence or resilience may increase an individual's allostatic load, making them more vulnerable to other health issues (Beckie, 2012). They make up a disproportionate percent of the "homeless" population and of those incarcerated in jails and prisons. In fact, an estimated 26% of people without a stable home/homeless and between one half to one quarter of those living in prisons have a psychiatric illness (Fazel et al., 2016; James & Glaze, 2006; US HUD, 2010). Inconsistent access to quality, permanent housing

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¹ Geores & Gesler (1999) argue that policy oscillates between advocating for long term institutionalization as an option and the idea of "community integration." However, as large psychiatric hospitals close, in the UK as swing towards institutionalization looks more like become a "matrix" of spaces throughout urban area (Curtis, 2010). In the US, while group homes are prevalent, the streets, ER's, and prison systems hold a large number of those once supported by psychiatric hospitals whom the "community integration" policies have failed to bridge over (Yanos, 2007)

is an often cited barrier to a healthy and stable lifestyle (Grant & Weshues, 2010; Kyle & Dunn, 2008; Padgett, 2007; Roy, Rousseau, Fortier & Mottard, 2013).

While deinstitutionalization and community integration policy are portrayed as more just, pragmatically they have long been underfunded. For dwelling and occupation, the provision of therapeutic supportive environments has been a responsibility deferred to the states and in turn implementation has been inconsistent and filled with gaps (Geores & Gesler, 1999). Those already at the intersection of socio-economic and racial injustice have been most vulnerable to disappearing funds and services (Dear & Taylor, 1982; Dear & Wolch, 1987). Subject to isolation, substance use, and stigma many persons living with mental illness experience housing today as transitional and poorly coupled to a supportive community. Group homes and other forms of congregate housing offer some support and act as a blended space, both private and shared. "Congregate housing" has been discouraged by the Supreme Court decision *Olmstead v*. L.C. on the grounds that it is a form of discriminative segregation for those who could otherwise maintain an autonomous lifestyle if financially supported (Bazelon, 2009). However, in effect the affordability of urban areas forces those living on the sparse financial provisions of disability into specific areas of often short-term and lower quality housing in transitory communities which make the ideal of "community integration" more lip service than reality (Bazelon, 2009; Christensen & Byrne, 2014; Yanos, Stefancic, & Tsemberis, 2012). Choice is restricted by available funds and availability of supported housing, leading to "service dependent ghettos" where the affordability and place seem to to intersect (Dear & Wolch, 1987). The supported housing that does exist is often custodial in nature, very often with the choice amongst supported housing locations being either completely assumed by guardians or eliminated by the lack of the options (Geores & Gesler, 1999). The focus, that is to say, is more on shelter and basic

protection from harm (to self or "public") than on the fundamental meaning of home as a locus of identity and community. While some researchers have questioned the experiences of those dependent on this social safety net for housing, few have actually engaged in processes of both deconstructing what is meant by home and asking the people it serves to be an active voice in reimagining what it could be. This task of reworking and reimagining is the process this workshop, in the context of The Farm at Penny Lane, endeavors to initiate.

Theory of Home

One might approach this question of access to and experience of home for those living with mental illness within a number of theoretical frameworks. However, a nursing perspective, in which the human response to illness is the focus of care and a critical feminist framework, which also privileges the lived experiences of individuals, are innately complementary. While the critical feminist framework recognizes that everything is nested in wider systems of power and culture, it highlights the "lived experience"—perspectives, meanings, emotions, values, and logics of individuals-- as an access point to those systems (Blunt & Dowling, 2006; Dyck, 1998). Nursing also recognizes that the lived experience of illness or health is linked to physiology and the larger socioeconomic structures that inform an individual's behavior, risks, environment, etc, but interventions target that specific window of an individual's experience. As Andrews (2002) argues, nursing perspective, knowledge and theory is embedded in place. Separating care from care place and from all the places linked by people and resources to those care places effaces an essential facet of nursing practice. Liaschenko (1994), in turn, calls our attention to how nursing interfaces with home spaces, where intersecting frameworks can either conflict, cover up or strengthen each other and this interaction has everything to do with a self-reflective, critical

practice. So, these two perspectives, critical feminist geography and nursing philosophy overlap and intersect in a way that deepen our understanding and rethinking of home.

Feminist geographers of home have strongly critiqued the suburban ideal—a haven from work, a private place of individualism and idealized family life (Blunt & Dowling, 2006; Hayden, 2003). For women, traditionally excluded from the public domain, the home is a site of unrecognized labor and internment. Paralleling these overlooked experiences, those with mental illnesses have either been secluded in psychiatric facilities or excluded from labor and occupation by disability support programs. For this marginalized population, home has not always been the experience of a haven where one retreats from the public domain but a space laden with the experience of confinement and exile, marked by the incorporation of the *public domain* in the form of institutional caretakers and dependence on governmental financial support. This is of course not to say that these "intrusions" are unnecessary or unwanted but that the experience of home has been markedly at odds with the suburban ideal which seems to underpin the notion of "community integration."

While house and home are related, a conflation of the two must be critiqued in order to understand the tensions that exist if one's home is not coupled with one's shelter. There is an emotional quality of belonging that is necessary for shelter to be home. Emotional disconnect from one's shelter can make a house not a home, engendering dissonance between one's experience and the normative expectations of home space. Humanistic geographers, responding to the neglect of home as a concept, designated it as a locus of identity and centeredness. However, in doing so, they sometimes risk romanticizing home, overlooking the negative experiences of home that do not fit this definition (Brickell, 2012; Blunt & Dowling, 2006). Home, also may have been a place associated with traumatic experiences—abuse, disaster, or

exile-- look to the early life experiences of many LGBTQ-identified people (Blunt & Dowling, 2006). Discordant with the presumptions home being a locus of emotionally positive experiences, these voices exhibit the sometimes traumatic landscape underlying the word home.

Home does expand beyond the material shelter. To see it, as traditional Marxists portray home, as a subservient space to the labor sphere, or as a space that simply reproduces the social structure, is simplistic and disregards the essential work of homemakers. A feminist critique compels us to consider the emotional range that expands a traditional locus of security and normative identity to see it as more broadly a place of oppression and perhaps the possibility of resistance to this oppression. Spaces and places are embedded with power structures and so not only can they be oppressive, they can also become sites of change, places to transform those unequal dynamics. Through altering the space of home, changing its physically, introducing new embodied practices and expanding the people included within its walls, feminist geographers argue that the power structures embedded there might be altered as well. The feminist critique subverts the normative understandings of home by broadening it to include the identity that comes with occupation (if one's occupation is within the home) or independence (rather than family centered) or even as a place of the emotional rewards of community and connection rather than privacy (Blunt & Dowling, 2006). Home and housing, coupled in policy, perilously overlooks this variability and indicates a critique.

While critiquing the suburban ideal of home, feminist geographers also reclaim *home* as a site of resistance against this oppressive construction. Deconstructing the public and private spheres as indistinct and not necessarily oppositional, feminists, such as bell hooks, define home as a place of resistance against the normative patriarchal inscriptions on lives, bodies, and

spaces. Speaking as a feminist and woman of color she writes that home must necessarily be more flexible and creative for marginalized groups.

"At times, home is nowhere. At times one knows only extreme estrangement and alienation. Then home is no longer just one place. It is locations. Home is that place which enables and promotes varied and ever-changing perspectives, a place where one discovers new ways of seeing reality, frontiers of difference." (hooks, 2015, p. 148)

As she critiques the inadequacy of the dominant notion home for understanding the experiences of women of color, she offers a critical lens for understanding the experience of home for those with mental illness, another marginalized population. Though people with mental illness have complicated layers of intersecting identities, many also experience home as fragmented, as an ideal proffered by family, therapists and policy, as a place of internment and a place from which one was expelled (Kyle & Dunn, 2008; Padgett, 2007; Parr, Philo, & Burns, 2003; Roy, Rousseau, Fortier & Mottard, 2013). Persons with such splintered understandings might find a source of resilience in hooks' understanding of home as a place that "enables" someone, that exalts "difference" rather than shames it, that values "new ways of seeing reality." Like the "decolonized" peoples that hooks reflects on in her piece, participants in the home workshop at Penny Lane *have* created home, in the face of remarkable opposition. As much of the story is one of fragmentation and exile it is also one of creativity and resilience.

THE FARM AT PENNY LANE

The Farm at Penny Lane is a 40-acre community farm for those with mental illnesses, run by a non-profit partnered with University of North Carolina's Center for Excellence in Community

Mental Health. The farm endeavors to create a space that is not treatment focused nor diagnosis specific but rather cultivates general "wellness." Future plans for the property include a "wellness community" which would consist of fifteen "tiny homes." These sustainably built, energy efficient, and single occupancy houses would provide affordable, long-term housing.

Approximately a third of the tiny house residents would be people without a specifically diagnosed psychiatric illness. This overlaps with Penny Lane's mission to decrease stigma of by focusing on general wellness and intentional community integration. Programming for clients with diagnoses is interspersed with more general workdays, where people come regardless of diagnosis, to work on large farm projects and eat meals together. Their intention is a shift away from "community integration" policies, which conflate integration with scattered site housing but provide few to no means for actual supported interfacing of the new residents with the surrounding community.

Underlying Penny Lane's mission is a recognition of housing disparities and the significant impact these disparities have on health, wellness, and resilience for those living with mental illnesses. The founding motto "Food as medicine, farming as therapy, housing as healthcare," demonstrates their commitment to an often overlooked and unaddressed aspect of care. Not only do the leaders at Penny Lane seek to offer this to their community members but they see themselves as a model. Penny Lane works on the "multi-scalar" notion of home in which the individual experience of home is layered with social and cultural structures, limited by economic realities (Brickell, 2012). Penny Lane leaders engage with *policy* on home and attempt to address issues of access with a demonstration of innovative ways of conceptualizing housing and of wellness more generally. By doing this, not only is Penny Lane critiquing the current exclusion of those with mental illness from home and housing, they are actively engaging in processes to

do something about it. According to Brickell (2012), this "doing," reimagining and creating more inclusive spaces and places, is a fundamental yet missing part of many geographies of exclusion.

Penny Lane's notion of home and housing is a composite of traditional understandings of home and more alternative understandings. While embracing the somewhat traditional idea of home as "shelter, center of security and self-expression" (Blunt & Dowling, 2006, p. 10), the programming and the tiny homes projects prioritize environmental and economic sustainability. In doing so, the farm subverts the suburban ideal which, while superficially embracing a bucolic setting, often does so at expense of actual healthy relationships with the land and environmental resources. In an attempt to make the housing more sustainable and affordable, the leaders have zeroed in on "tiny homes." One might argue that "tiny homes," miniaturized housing that balances a normative home aesthetic with spatial and energy efficiency, are more palatable versions of trailers and mobile homes which have long been regarded as "unhomely." While for those that live in them, mobile homes may offer access to an otherwise unfordable understanding of home, government policies and businesses often enforce exclusion of these specific types of shelters with zoning laws and financing options (Blunt & Dowling, 2006). It may be that the tiny home concept, as utilized by Penny Lane is essential in garnering support from stakeholders (including potential residents). However, the affordability and community aspect of the housing separates it from purely a suburban, mainstream conceptualization of home.

Unquestionably, Penny Lane engages the lived experience of those with mental illnesses. In its prototype house, leaders invited feedback from regular clients who had the opportunity to "test run" the house for a week. Much of the work Penny Lane engages in is on a socioeconomic level, negotiating client resources and needs with current zoning laws, state and federal housing policies, and funders. Their most innovative and critical work is behind the scenes. The farm is

not only tasked with building the homes and generating programming but also with out how to support and create a place like the farm within sociopolitical and economic regulations. Programming is still being developed and much of the focus on the actual experience in the space is more about providing time and resources for people to meet. A critical feminist approach to home, privileging lived experiences, emotional meanings, and the voices of those with mental illnesses has the potential to add a rich layer to the Farm's practice of creating healthy homes for and with people living with mental illness. This workshop's intent was to amplify the lived experiences of the participants and provide another space for them to critical engage with the Farm's work on homes. This in turn deepens the transformative place of Penny Lane, where home is both understood as a fundamental right and reconstructed to be a more inclusive, flexible space.

PARTICIPATORY ACTION FRAMEWORK: A PROCESS FOR BUILDING RESILIENCE AND KNOWLEDGE

Participatory action research is a critical form of qualitative grounded theory research and fits into the setting of Penny Lane, critical feminist geography, and to the goals of this project. In a series of four workshops, with six to eight participants from the farm, I shared this approach and utilized it in an attempt to facilitate a reflection on commonly held assumptions of home, participants' experiences, and to cultivate a new definition of home that was perhaps more inclusive. Participatory action research emphasizes equalized power dynamics in knowledge and knowledge formation and emphasizes process as much as outcome (Kidd, Kenny & McKinstry, 2014). In these ways, despite often being neglected by nurse researchers, it actually

complements the nursing model of empowering patients and partnering with them for person centered care (Walter, 2016).

One intention of the model is to close the gap between researcher and participant. In healthcare research this can mean correcting unequal power and knowledge dynamics between provider and patient. Especially for people with mental illnesses, so often robbed explicitly of both ontological security and choice in treatment by the illness, participatory action research can serve an important role in cultivating resilience. Active not only in discussion at hand but in the generation of future conversations, participants are offered space to be collaborators with facilitators in the aims of the project/research (Soltis-Jarrett, 1997; 2004). While I brought my own set of interests, questions and objectives, the voices of participants were prioritized and guided the discourse of the workshops. The course of each workshop led to the following week's discussion. This process and structure disrupts traditional reductive research methods. While one aim *is* to understand the lived experience of the participants, it is also to expand this understanding by offering new and more empowered roles in knowledge formation with a chance to increase resiliency in the process.

Central to changing the power structures is addressing knowledge and knowledge formation. In a participatory action framework, knowledge is seen as dialectical, a back and forth between nurse-facilitator and participant. Rather than extraction of qualitative data from interviews, the workshop was a dialogue amongst all participants.

(The process) . . . ". . . ignites the nurse- facilitator and the participants to work together to coidentify, councover, cochallenge, and potentially cotransform the ways information, concerns, and needs are defined, demonstrated, and "lived out" among the individuals, groups, and families who have no control over the

authority and power of that "information" and/or knowledge." (Soltis Jarrett, 2004, p. 316)

This collaborative approach to understanding home is key to deconstructing current conceptions. In prioritizing a more egalitarian process of knowledge formation it offers power to produce knowledge, understand one's own experience to those traditionally deprived of this power. To engage in this attempt to balance power asymmetries, participatory action research demands self-reflexive awareness of those power imbalances, it demands work from the facilitator to be self-aware of the power inherent in their position. The process was *as essential as* the knowledge generated by the workshop and impacted not only participants but facilitators as well.

Nursing, especially psychiatric mental health nursing, has long prioritized interpersonal relationships which are also core to the participatory action approach (Barker, 2001).

Collaboration, as Soltis-Jarrett identifies above, is key in nursing relationships with patients. As researchers, nurses owe a complicated blend of accountability to both the project and the patient; the structure of participatory based research leaves room for this multidirectional accountability (Seng, 1998). Not only does this process of participatory research fit into the nursing model it offers an avenue for engaging in social justice work. As carers working at the interface of individual clients with healthcare systems, nurses witness social injustices but without engaging in organizational policy work, and often having to leave the bedside to do so, they have difficulty engaging in social justice work. Participatory action research is an opportunity to blend these two similar frameworks.

The following was the result of incorporating the participatory action research framework into four workshops, held weekly at the Farm at Penny Lane. The workshop consisted of two nurse-facilitators and six to eight participants who were recruited through other programming at

Penny Lane and a newsletter. Importantly non-diagnosis specific, the workshop was a combination of discussion and activities. We planted houseplants, mapped our homes, communities, and support systems and shared meals. These discussions acted as a spring board for future programming at Penny Lane, providing insight into the process and a window into how much we have to learn and create when it comes to home.

Homes Workshop at Penny Lane

Introducing Participatory Action Framework & My Positionality.

The participatory action framework was clearly new and almost uncomfortable to the group—it offers a great deal of responsibility to the facilitator but also to the participants. To ignite the first discussion, I invited participants to consider the materiality of their "home" or shelter. With my background in environmental sustainability and nursing, and in the setting of Penny Lane, I hoped that reflecting on ways to physically alter home spaces, might help highlight the connections our wellness has to our environment. Feminist critique and disability studies have often focused on how the material space of a house is not neutral but rather that cultural expectations and norms are layered into the arrangement, design and make up of houses. Seemingly benign house spaces enforce gender roles or decrease one's ability to be independent and well (Blunt & Dowling, 2006; Dyck, 1998).

However, within this first discussion it became evident that my concern with the materiality of the home was not shared by the participants. How can one affect change in a material space when one's control over even that seemingly simple thing, the materiality, is minimal at best? These dwelling spaces were not actually *home* for the majority of the participants. Whatever was missing or whatever was there that kept them from feeling at home (the discussion of which

follows) kept many of the participants from seriously engaging in their dwellings. As D. a middle aged woman with a flare for style and a performative nature declared, "It's not my home, I hate that place, I *despise* it. I moved there 2 years ago and I *refuse* to unpack my boxes. It's a horrible, horrible place."

However, it was not that participants did not understand or identify materiality of their dwelling space and its impact on their well being. It was more that they felt lacking in the resources and power to change those spaces. K., a middle aged man who lives in his sister's rental property, did attempt to change his space by identifying where the light was in the room and at what time of day by using a houseplant potted during the workshop. However, his interest in the space was almost singular amongst the participants and perhaps marked by his dwelling being the closest to a commonly held ideal: a house, well-furnished, where he lived independently. D related that her house was undesirable in part because it was so cold—but there was nothing to be done—the landlord wouldn't fix the furnace and space heaters drove up the bills. L., who is in her early 20's and lives with her parents, says she tried to put plants in her house because she felt they connected her to the land, but her parents wouldn't allow it except in her room where there was insufficient light. Even for B., a young man who professed to love his rental where he's lived more or less stable for several years, there was a limit on the ability to totally engage with the materiality of the home. For one, he pointed out, it's a rental and even though he loves houseplants there's not enough light. Aside from what houseplants he could manage, his understanding of the "materiality" of his house centered around televisions, videogames and drinking, all means to occupying his time. A recent job may offer an opportunity to make his relationship with his house more normative—however at the time, his house was a place of both haven and seclusion, both retreat and isolation. His access to this home is jeopardized every time his housemate changes. Would he get on with the next person? Would he be able to find someone? Would he have to leave?

Of course these are not preoccupations unique to these participants; many people, even without a diagnosis, face similar limitations to prioritizing their engagement with the materiality of wherever they dwell. However, these opening discussions highlighted how altering the materiality of a dwelling was less of an option for increasing resilience, supporting healthy routines, or making dwelling more "home" than I'd originally conceived. Furthermore, this modification to my own assumptions demonstrates a fundamental underpinning of participatory action frameworks, in which the facilitator is not passive in the group's discourse but actively, and intimately, involved in the process of knowledge transformation.

House is not always home

For a multiplicity of reasons, house was not *home* for many of the workshop participants. That is their dwellings did not match a commonly held ideal of home. Generalized research into the "meaning" of home for those in the Global North world has described with regularity home as (1) "providing shelter," (2) "a setting for people to feel secure and centered" (3) "a place through which one's sense of self may be expressed" (Blunt & Dowling, 2006, p. 9). Within many degrees of privilege, this is a somewhat flexible ideal. However, if accessing it has been continuously frustrated and fragmented—as is the experience of many of the participants—the importance and the location of "home" conceivably may not be found beneath one's roof.

Despite many of the participants being relatively stable and supported, their housing was never their own—a lack of proprietorship and the lack of financial resources to ever secure one's own house limited both security and self-expression. Access to housing was restricted by income and so was the quality of the dwelling and length of time that they could afford to stay in their

houses. This overlaps with research on community integration for those with mental illnesses. Housing permanence, as it is for many living in poverty is a challenge for community building (Yanos, Stefancic, & Tsemberis, 2012). Even for the participants who liked their home and felt relatively centered, their sense of security was under threat of jeopardized finances. As B. and also H. (a woman who had moved here recently from up North) had described their chosen house where they lived in relative independence as hinged on an agreeable housemate. Both were in the process of finding new housemates. Not only did they have to negotiate the basic tenants of sharing a living space but also the stigma associated with mental illness.

Lack of privacy in housing limited self-expression. As W. described in her group home, the common room is not a space of "commonness." While studies show that group homes, if developmentally appropriate, *can be* a link to peer support (Abrahamson, 2014; Roy, Rousseau, Fortier & Mottard, 2013). However, within W.'s experience, the group home was simply a house occupied as if with separate apartments. The dwellers didn't seem to have an interest in interacting. As it existed for her, the common spaces were simply functional rooms for all the group home residents, overlapping yet hardly intersecting in a meaningful way. She didn't reject the support of her group home but did identify the limitations on her expression: she keeps to herself in her room, things in the common areas may be broken by others in moments of crisis. Even within her room she keeps the sound on her music and television low, she attempts to occupy her time with quiet, distracting activities. The one thing that allows for some element of self-expression is a crocheted blanket she made. Similarly, Y. a young man in his early 20's, describes his bed as his sole center of privacy. Even this he shares sometimes with a crowded house of a rotating group of fifteen people. Relating that he enjoys drawing as a form of self-

expression he remarks that there is hardly a space to do so in his house, not even sitting up in bed because someone is usually trying to sleep.

For all of the participants, there was a lack of choice in housing. There is some evidence that providing *choice* for clients is a factor in ensuring that the supportive housing is successful. Choice seems to prevent people from leaving and promotes residents' health status (Grant & Westhues, 2010; Roy, Rousseau, Fortier & Mottard, 2013). The way in which lack of choice manifested for several of the participants was in confinement to home by lack of transportation and lack of occupation. Disability laws limit allowable income and prevent many from taking any kind of job. Excluded from the daily routines that occupy so many others, the participants were at home not always by choice but because there were no other options. Public space is limited in the diversity of activities it offers. Financial realities limit participation in leisure activities that those not prevented from working by disability laws might think to occupy "free time." W., K., and S. are older participants who have lived on disability for a number of years, a main preoccupation was dispelling boredom. Boredom inherent in being confined to home was almost threatening. It was in the silence and isolation that invasive thoughts and symptoms of their illnesses seemed most acute. Additionally, lack of transportation, either because vehicles were unaffordable or because their license had been taken away, also contributed to this lack of choice. Even a house which was stable and integrated into the community became a place of confinement rather than security. K. could drive but was dependent on his father for gas money. After tracking his anxiety and calmness throughout several days he noted that his anxiety spiked just as he was about to run out of gas money, and was eased by his father's replenishment. It scared him, made him feel trapped, to lose the opportunity to meet the already minimal commitments he had made in his week.

Perhaps, most of all, houses were not home because many of the participants saw their current housing as a representation of rejection from a home that they had once experienced. Whether it was a childhood home or an apartment owned before their illness came to crisis—this idealized home was a place from which the participants had been exiled by both individuals and larger systems of power. For L., the *house* she lived in was her parents, her *home* had been the place she grew up in California. Key to this exile was that there could be no true return. The rejection was in a way a bitter convolution of these once-homes. For H. the home she left in the North had rejected her. She came to NC seeking a new start. Yet, even here, her aspirations were splintered. Her roommate spurned her after a hospitalization and her daughter eventually returned to her mother's guardianship up North. For D. the trauma she had experienced her in original home had marred it so thoroughly she was unable to return, it was in this new house, the one she described as "horrible," that she was exiled.

Home was a place that had been but was not any longer. It was a place from which they had been so forcefully rejected that they could not return. Housing was often a symbol of this rejection and abjectly not home. That house and home were not conflated, that the notion of home seemed difficult for the participants to focus on. It was rooted in this complicated relationship with their pasts and their experience of mental illness. Like many aspects of their lives, home had been destabilized, something that marked them apart from mainstream society. Some outright dismissed the notion of home as attainable. Their fractured experience of home was just another in a list of those which made them essentially different. For other participants, home was a tired ideal that seemed as far off as independence and autonomy. Even for those who's housing most closely mirrored a conventional home there was a destabilizing sense that it would always be different, merely a mock up of what others came by easily.

Home is in the people, places, and embodied practices that make us feel belonging.

It was from this fractured experience of home and housing, that, as a workshop, we began to look for where home might be. In this search, hooks' words echo and are most salient: "At times, home is nowhere. At times one knows only extreme estrangement and alienation. Then home is no longer just one place." (hooks, 2015 p. 148). Our discussions in the following workshops reflected on an exploration of home as a "place," a set of people, or practices which permit "new ways of seeing reality, frontiers of difference." To be estranged from home on the basis of one's difference is an isolating experience. However, Penny Lane embraces these differences (i.e. mental illness diagnosis and the range of behavioral and social needs). It offers a home and a community that doesn't overtly treat or attempt to nullify differences. Instead, Penny Lane provides space for the process of destignatizing them. A similar space can be fostered in social art projects, patently not clinical, which provide stability and belonging and offer the satisfying "boundedness" of a finished product, not unlike farm work (Curtis, 2010, p. 209). Because home and housing, even if secured, were not accessible for homemaking processes, our focus became what was accessible: a feeling of home. By identifying where, when, or with whom this "feeling" occurred, our goal became to illuminate another definition of home. This definition could be one that might be more accessible and usable for the community at Penny Lane and in the individual lives of community members. Ultimately, the hope was to engender resilience in tandem with the setting of Penny Lane-- both a place for this exploration and critique of home and an organization working to address material access concerns.

For several of the participants, this *feeling at home* was either working on the farm or walking in the woods, when no other people were around. H. thought of the woods as accepting and a setting that heightened her senses; she felt *natural* as she never did elsewhere. In the perspective

of L., the woods near her house were both a place of freedom from her oppressive family and a place that connected her to other places with similarities she felt were echoed in a particular ridge line or creek. Matching the familiarity of a place to another once on the periphery of home was a way of returning to that place she'd been exiled. For S., the safety of the farm and the mark he felt he made on the land was reassuring. After his inpatient stay, the trench he'd built was still there, as if it was a place that accepted his actions, his behavior, embraced him rather than writing him off, exiling him even as he was in crisis.

Another "feeling at home" was not in any specific location but in embodied practices, T., a young woman who lived with many resources and a supportive parent, found that *feeling* riding horses. Social and developmental delays, to which she fully attested, made many other social interactions stressful or boring for her. However, riding horses was freeing and how she felt her most competent self. Her room was covered in drawings of horses, she was at every moment ready to reference them. Riding was a practice in which, even when she could not fully engage physically, she took refuge in thought. For L., it was a set of intentional movement practices called "eco-somatics." These dance like movement meditations, rooted in environmental cues like seasons and landscapes, helped her feel at home anywhere she could practice them. Practices that called attention to her body and her movement through space helped her find her body as "home." She felt these practices that fostered centeredness and self-expression, were especially important, as a person who identified as transgender. Despite the rejection of the general public, especially recently with HB2 and the election, she was able to call up a sense of security in her eco-somatic practices and through them find home and solidarity with an environment itself endangered by the wider world. Not only did these practices help her feel more at home in her

body and see her plight as one paralleled by the earth's, but also they connected her with others who used the eco-somatic practices.

Often home and house are associated with family but many of the participants found that feeling of home with those who explicitly and un-ambiguously accepted them rather than in familial ties. After moving here in the summer, H. said she had found a group of "weird" and "playful" people who celebrated differences but with respectful curiosity rather than deliberate prying. She could be a "kid" though she had her own daughter. The friends called her up and expected her to be places with them. She never felt that these were, as previous social arrangements had been, pity social calls. Their welcoming acceptance was similar to what she sought and found at Penny Lane. For Y., he found his relationship with a peer friend to be the closest he'd ever "felt at home." This friend was like a brother but closer, because his family had never actually been this close. Y. knew that when all else was in crisis he could go to his friend who offered that centeredness, security, sometimes even shelter, that supposedly is "home." Home is for the making

During one of the last workshops, as an activity, I suggested we attempt to map home as we had discussed it: a feeling. All these people, places, and embodied practices occur in relationship to each other and to the individual participant. As an exercise, I suggested spatially representing these connections might help us understand how they fit in with each other. Could we "see" connections previously unaccounted for? As a facilitator, part of my goal was to offer opportunities outside of pure "words" for expression of experience. Many people followed my own model of what "mapping" could look like. Y., who says he likes to draw in his free time, did something different. He drew a puzzle, each interlocking piece represented a person, place, or

practice in which he felt "at home." The puzzle, he explained, was unfinished because he's still making it.

The hour every week offered a space to redefine home, to value the voices of the participants and transform power dynamics from patient/provider to collaborators. However, as we pursued these goals of new knowledge and knowledge making we were engaging in "home making processes" at Penny Lane. The hour served to foster another piece of Y.'s, and all the participants' puzzle.

Each week's workshop was structured with an opening check-in and meditation. Both these practices allowed for the group members to identify each other as a cohesive group and as individuals. Each week closed with tea and a small meal. These activities, along with the collaboration and exploration done as a group—provided time and resources for creating a sense of "home" at Penny Lane. In the ways that the participants described their houses were not home, the workshop was a home. As a microcosm for Penny Lane, the weekly workshop: offered a stigma-free space, fostered independence, and facilitated choice and resilience by encouraging contribution to knowledge formation. The workshop also offered space for participant identified ways to "feel at home" by involving embodied practices based on mindful meditation and ecosomatics (as per request of L.), being explicitly welcoming, and offering friendships of peers outside the typical family or community roles. L., naturally a shy personality, was able to introduce eco-somatics to the group. H. shared what she knew about mindful eating and giving thanks to one's food. Participants encouraged W. to share her crocheting skills by leading a program upcoming in the winter months. Even H. was able to offer tea and snacks one week and Y. advised H. and L. on housing possibilities as both faced impending change. The workshop not only fostered new understandings of home but actively put those understandings into practice.

These home-making processes are slow and messy, but in the context of an action-focused environment like Penny Lane they are possible. As hooks (2015, p. 148) describes in her reflection "Home is that place which enables and promotes varied and ever-changing perspectives." Not only did the workshop in the context of other programming at Penny Lane, *promote* new perspectives on living with a mental illness and on mental and total wellness, it enacted these perspectives. Still building capacity, workshops such as this one offer a collaborative space for input and change.

NURSING IMPLICATIONS

In hospitals the overriding model of care is medical focused, nursing care often flexes towards serving the "medical gaze." This transcends care to research where the vast majority of nursing research engages in the reductive models. It is important not to discount the value of this work, nor ignore the wealth of nursing work that *does* draw on participatory frameworks. But hopefully this workshop serves as a supporting example of the importance of participatory action research and its relevance to the nursing model. Home and housing is an intimate setting highly tied to the individual. It is a place, in hospital nursing, that is rarely seen but often referenced. In the hospital and outside its walls it is clear that housing, and perhaps also *home*, is part and parcel of total wellness. A participatory action framework allowed for important collaboration, not only for participants to share their own view of housing and home but for facilitators to probe the ideal of home. Both facilitator and participant endeavor to "coidentify, councover, cochallenge, and potentially cotransform" the understandings of home and community and even health (Soltis Jarrett, 2004, p. 316).

Nursing outside the hospital

In her seminal work on the nursing and the geography of home care, Liaschenko (1994) examines the ways in which psychiatric and home care nurses interact in often over looked environments of home space. There is a tension, Liaschenko identifies, always present in nursing but accentuated in home care between a "medical gaze" and a "nursing gaze." Tracing the historical roots of medicine, nursing and the practice of observation, Liaschenko comments on the tenuous space nursing occupies between physicians and patients, as the observers — eyes and ears—of the medical gaze as well as patient advocates. "To be home is to be an agent of your own life" (Liaschenko, 1994, p. 22). In the home, nursing is a role that imports an institution and also offers to be an advocate on behalf of a patient to an institution. Navigating this nuanced terrain can be laborious and risks being an outright dismissed endeavor.

Liaschenko, like Penny Lane, asks us to consider healthcare beyond the institution, to consider the patient and their worldview instead of the biomedical one. The gaze of the physician is not the gaze of any particular physician but the gaze of the medical institutions which attempt to trespass on the most intimate portions of an individual's life. The lives of those with chronic illness or aging are particularly vulnerable to this trespassing. Liaschenko describes the nursing gaze as stereoscopic. Reminding us of Nightingale's caution on observation--- it should be for the purpose of "increasing health and comfort." Liaschenko insists that a stereoscopic vision allows nurses consider the biomedical model of disease but also advocated for patients on:

"what it means to have a life; to articulate it more forcefully; to continue to develop nurse run facilities; to continue to insist on a seat at the table of power where the control of space and time are set, . . . and to have the courage to act in accordance with our gaze." (Liaschenko, 1994, p. 25)

Housing, implicated in health disparities must expand its formulation beyond shelter and incorporate the complicated dimensions of home. In accord with the recognition of diverse and different experiences of home, of the sometimes oppressive effect of ideals and assumptions of home, nurses play a key role in advocating for the creation of spaces, places and communities based on the voices of their patients, the needs that go beyond the physical needs of shelter to the depths of what, in a place, affords us comfort, wellness and resilience.

CONCLUSION

In the workshop, participants were able to engage with each other to both identify ideal and different experiences of home as well as to collaborate in a new shared space, a genesis of a new place of home at Penny Lane. Using a participatory action framework, in which knowledge and creation of knowledge was shared amongst participants and facilitators, the project engendered more egalitarian power dynamics. By deconstructing the patient/provider, subject/researcher dualism that typifies the medical field, the workshop became more closely aligned with patient centered partnerships that underpin nursing care. Finally, by reflecting on this experience of home through the lens of critical feminist geography, the unique knowledge of those living with mental illness not only becomes relevant but integral to providing housing and community integration in the post-asylum era. Housing simply is not enough, these spaces must be open and supportive of alternative "home-making processes" which open up definitions of home and make them more inclusive. If lack of access to long term housing truly is a contributing factor in health disparities making the idea of home accessible-- that is making housing a place of belonging as much as shelter-- is an important process. It is a process that not only should include clients of such housing policy but *must*.

During the workshop, participants described several ways in which their *houses* could not be described as "home." Self-expression and centeredness, both normative assumptions on the qualities of a home that go beyond shelter, are forms of security (Blunt & Dowling, 2006). While some participants did find a kind of home in their house, all of the participants described a lack of security in their houses. Either this insecurity was financial or in a limitation to their autonomy. Dependent on families and caregivers, participants are prevented from achieving appropriate developmental roles. Symptoms and policies on disability income limited participants from having meaningful jobs or having a car and so house was a place of confinement rather than a haven. Their houses were not free from the stigma of their diagnosis as several faced in their search for housemates.

Not only were current houses far from traditional ideal homes, many of the participants had experienced a kind of exclusion, exile from past homes which maybe have been considered more ideal. An ethnographic work on the Scottish asylum, Craig Dunain, describes the diaspora of both residents and workers after it had closed and how the place, despite its complexities was still considered *home* (Parr, Philo, & Burns, 2003). In the contemporary post-asylum geography, those with mental illnesses find themselves expelled from long term psychiatric hospitals, but also from inpatient units (more quickly than ever before), and their family's home, and have no where to go (Rose & Gerson, 2012). More critically, we might locate these vulnerable populations in the "new asylum:" prisons, jails, ERs and the street (Yanos, 2007). This lack of rootedness is evident in D.'s testimony, unable to unpack and unable to return. Displaced from home and faced with a lack of financial resources, those with mental illness find themselves relegated to low income, short-term housing. With their involuntary displacement, the parallels

with refugees is not such as stretch, and people with mental illnesses may have suffered similarly damaging impacts from such rootlessness (Curtis, 2010; Dear & Wolch, 1987).

In these troubling and often overlooked experiences, participants were able to identify a nested emotional geography of home. While not always a single fixed location, the "home" that the participants *felt* did always implicate some sense of place. For those who found it in friends, their relationships were tied to the place they fostered those relationships, ranging from the street to the city of Chapel Hill as a uniquely liberal and accepting corner of the south. For those who found it in embodied practices (like eco-somatic movement and horseback riding) their practices were a way of linking them to the land, it was in this link and connection and expertise that they felt most themselves and most "at home." Then there were those who found it in the woods and the Farm and this was based partially on an absence of stigma from these spaces and places. In the woods and on the farm there are no the judgmental eyes of house-mates, people on the street or even providers. These are spaces where one can leave one's mark or not, walk, talk, dance, ride, test one's identity and shape it as Parr identified as an important process in her account of "drop in" clinics in Nottingham (Parr, 2000).

The workshop itself became a site of homemaking processes. Home, whether normative or reimagined, for most, has a deeply spatial component. Each week we pulled together chairs around a table, boiled water for tea, and dished out snacks and small meals. Before delving in, we discussed our week with each other in a circle. We utilized the space at Penny Lane with its mission to reduce health and housing disparities for those with mental illness, though we could have used any community setting. The setting and practices each week were key in actively cultivating a new space. We utilized traditional home making processes, like food sharing, for building a non-traditional home (Curtis, 2010). Each program at Penny Lane linked its

participants to each other, to other programming, and to the Farm, thus fostering a future space of inclusiveness. The Farm embraces these alternative ways of understanding home—as friends not just family, of communal spaces not just private ones, and is in this way, enables "new ways of seeing reality" (hooks, 2015, p.148). Place is both material and emotional (Blunt, 2005) and so home making processes are both material and imaginary. Penny Lane, as a new pace, is flexible enough to permit such explorations of the meaning of home in workshops like this.

As many of the participants have had fragmented experiences with home such processes are key to working toward a more inclusive definition and to making the Farm at Penny Lane a viable home. Parr (2000) and Curtis (2010) have described decentralized places in the postasylum geography of mental health that are "transitional" or "semi-institutional" in nature. On one hand, Penny Lane falls into this class of space. It endeavors to be a community space without treatment or stigma similar to the "drop-ins" that Parr describes but is contradictorily funded and supported through UNC Psychiatry. This tension is perhaps unavoidable within our current structures of funding. On the other hand, Penny Lane is engaging with the issue of housing, often seen as separate kind of "support" in a deinstitutionalized landscape. Much focus in this segment of housing studies is on the tension between "group supported living" and scattered site housing with the aim of community integration (Yanos, 2007). Penny Lane walks the boundary between the two. Other programming, that offers community space and housing combined with innovative programming, does so for a steep price. One of the objectives of Penny Lane is to offer this rare blend at a cost accessible to all those interested. Workshops like this one add another layer of complexity to the space that Penny Lane seeks to provide by helping understand and redefine the experience of home. The leaders of Penny Lane, meanwhile, navigate the interface of public policy, court decisions, funding and zoning with regard to their

mission. As a whole, the organization is dealing with the many intersecting entities of home. The emotional geographies that the participants explored in the workshop stand alone are incomplete but in the context of Penny Lane are critical.

Penny Lane is in a unique situation, even more than the transitional/semi-institutional spaces that Parr (2000) and Curtis (2010) identify. Only one of the full-time staff at Penny Lane is a "professional" in the field of mental health. While he does much to draw in cliental from local community mental health groups such as ACT, he does not actually engage in the scope of his practice at Penny Lane. The other two consistent staff at Penny Lane are a project manager and the farm manager. They specifically identify as not being "professionals" in this field and do not bring any attempt to diagnosis or provide interventions. Instead they act as facilitators. The farm does draw on UNC for student experiences but also from a range of expertise and interests and only for the ability to provide cost effective and affordable programming geared toward the volunteered interests of cliental. The focus is on providing time and space to utilize the land rather than on specific treatment. There is a sense that the land itself is therapeutic, the process of home making and community building organic. In this way, Penny Lane endeavors to create a space that as much as it provides a home also draws "professionals" from nursing, psychiatry and allied health out of their institutions and into genuine community spaces. By decoupling these professionals from handles like diagnoses and interventions and introducing them to individuals, Penny Lane is creating a template for a space and place that is singular in its accessibility and structure.

In an era of policy encouraging community integration there is a temptation to create policy and homes that erase difference. However, based on the voices heard in this workshop and more generally at Penny Lane, different experiences affect access to "home." If the policy hopes to

provide effective housing solutions, "home as medicine," it must more fully consider the emotional registers of home. Experiences are often different and usually complex. Yearning for, or perhaps rejecting, belonging that others take for granted, participants forged this "at home"-ness in new places, people and practices. Integration should not mean sublimation of these experiences. However, without romanticizing "alternative visions" (Curtis, 2010, p. 158) places like Penny Lane may offer communities where difference is not considered in tension with an ideal or lacking in the substance to obtain such an ideal. By structuring the intentions of homemaking processes to include alternative material relations --like food access and sustainability-- along with more emotional dimensions --like alternative family structures, embodied practices, and non-stigmatizing, non-therapy focused environments-- Penny Lane presents an option that combines the best of supported housing and the ideals of community integration. Constitutive to providing "home" beyond housing is a critique of the very idea of home that is embraced by housing and community integration policy.

This is a critique most rich when it includes the analysis by people marginalized by power structures. However, power structures surrounding knowledge production are deeply ingrained and spaces must be intentionally cultivated and facilitated to empower participants to deconstruct their own experiences and amplify their voices. Penny Lane actively engages in alternative homemaking processes which open up the many dimensions of home to its community members. In doing so, not only do they question what home and wellness should and could be for people with mental illnesses they also question what it could be also for all of us.

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