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## Throwing Pebbles While Waiting: An Autoethnographic Exploration of Mental Health and Colonialism

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### Abstract

In this article, three scholars jointly investigate questions of Western colonization and mental health. While their areas of interest and experience vary, the authors discuss oppression as a common thread connecting their ideas about mental health and its medicalization. In line with Toyosaki et al. (2009), the researchers did a community autoethnography, performing written dialogue as a dynamic research method. Using a sequential model, Kelly Limes Taylor wrote about her experience, passed it on to Rita Sørly and Bengt Karlsson. Karlsson added his story to the previous writing, and he passed it on to Sørly for further addition of stories. Sørly passed the stories added to Limes Taylor, which added new reflections. Together, the three researchers explore various questions: Who determines what is normal or humane in our society, and who gets left out of those decisions? Do mental health providers make a positive difference, or are they merely legalizing new forms of oppression? What happens when one simply cannot mentally assimilate the dominant narratives that excuse oppression, environmental destruction, and/or insatiable economic practice? Through the lens of their own experience, Limes Taylor, Sørly, and Karlsson share their thoughts on these and other questions as they jointly explore ideas of mental health identity in the context of Western colonialism.

### Keywords

mental health, colonialism, autoethnography

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# Throwing Pebbles While Waiting: An Autoethnographic Exploration of Mental Health and Colonialism

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## **Abstract:**

In this article, three scholars jointly investigate questions of Western colonization and mental health. While their areas of interest and experience vary, the authors discuss oppression as a common thread connecting their ideas about mental health and its medicalization. In line with Toyosaki (2009), the researchers did a community autoethnography, performing written dialogue as a dynamic research method. Using a sequential model, Kelly Limes Taylor wrote about her experience, passed it on to Rita Sørly and Bengt Karlsson. Karlsson added his story to the previous writing, and he passed it on to Sørly for further addition of stories. Sørly passed the stories added to Limes Taylor, which added new reflections. Together, the three researchers explore various questions. Who determines what is normal or humane in our society, and who gets left out of those decisions? Do mental health providers actually make a positive difference, or are they merely legalizing new forms of oppression? What happens when one simply cannot mentally assimilate the dominant narratives that excuse oppression, environmental destruction, and/or insatiable economic practice? Through the lens of their own experience, Limes Taylor, Sørly and Karlsson share their thoughts on these and other questions as they jointly explore ideas of mental health identity in the context of Western colonialism.

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## **An autoethnographic choice**

Qualitative research was considered an appropriate choice of method for our work, as it is a situated activity that locates us researchers as observers in the world (Denzin and Lincoln, 2013). Qualitative methods consist of a set of interpretive, material practices that not only make the world visible, but it also transforms the world. The world is turned into a series of representations – fieldnotes, interviews, conversations, photographs, recording and stories, where we study things in their natural settings, attempting to *'make sense of or interpret phenomena in terms of the meaning people bring to them'* (Denzin and Lincoln, 2013, p.7). The researchers may be seen as makers of quilts, *bricoleurs*, producing bricolages of material; a pieced- together set of representations fitted to a complex situation (ibid.) in a specific context. While working with qualitative representations, improvising, creating and listening to each other stories blending together, overlapping and forming new creations, we decided to use our stories in an autoethnographic manner. Using personal experiences (“auto”) to describe and interpret (“graphy”) cultural experiences, beliefs, and practices (“ethno”) underline the need for reflexivity while doing research (Adams, Ellis and Holman Jones, 2017).

Autoethnography is both a research method and a distinct way of writing, but more than a representation of one's own experiences. The goal is to create a text that can represent a dialogical approach to culture *and* experiences (Karlsson and Sørly, 2021). Some authors suggest that the main idea of autoethnography is of personal narratives addressing central theoretical debates in sociology (Laslett, 1999; Aure, 2019), and, we add, in other social and health disciplines.

As researchers we had an aim with our work; to envision and engage in critical community building that works to resituate identified social, cultural and sensitive issues (Toyosaki et al, 2009) related to mental health and colonialism. While working with each other's stories, we found that we were working with community autoethnography. This can be defined as (1) an intimate research methodology for self- discovery and self- construction, (2) a relationship-making activity among researchers who participate in and co -construct each other's existence, and (3) a topic- centered and interpretive approach which helps its participants create a safe

environment gaining in depth understanding of the topic (Toyosaki et al, 2009) – in our case, mental health, and colonialism.

We shared written stories with each other. Our autoethnographic pieces, all written within the frame of mental health and colonialism, were sent in the following manner: Limes Taylor wrote about her experience, passed it on to Sørly and Karlsson. Karlsson added his story to the previous writing and passed it on to Sørly for further reflections and addition of stories. Sørly passed the stories added to Limes Taylor, which added new reflections, closing the process for now. Each author analyzed the received story, using a social perspective, taking on the other's perspective, for building a communal relationship, before passing it on to the other authors. The community- autoethnographic writing process rests upon reflexivity, recognizing the effect of the self on a context as a necessary constituent of the context and vice versa (Toyosaki, 2009, p.77). In line with Toyosaki et al (2009), we see community autoethnography as a way of doing cultural criticism through breaking silence, encouraging perspectives taken, and work towards social change.

The results of this process are presented as texts in a dynamic movement between the researchers. We all shared stories, reflecting and giving new perspectives to each other. We have chosen to present the work in the following order: Kelly's story, Bengt's reflections on Kelly's story and a new story, Rita's response to these stories and adding of a story, and finally, Kelly's reflections upon the whole process.

Our research is placed within a certain sociocultural position, and our value systems have affected our writing. The research, the design of our work, and the analysis of data is a way of fighting against marginalization and colonialism within a mental health context. That does not impair the quality of our research. On the other hand, we find, through dynamical processes of reflexivity and writing, to be ensuring concepts such as trustworthiness, credibility, trustworthiness and relevance. Each author is responsible for ensuring quality in the research process.

As our research is based on our own stories and reflections and does not include interviews or other data with participants, there was no need for approval from Institutional Review Boards, or

other ethical committees. The study referred to by Rita Sørly, on user involvement among Sami mental health service users, was supported by the Sami Parliament (HS 003/18) and Sámi Norwegian National Advisory Unit on Mental Health and Substance Abuse (S- 07 2018).

### **Kelly Limes Taylor: Beginnings**

For a few years now, I've been writing about knowledge-based oppression in the United States context. More specifically, I've written about (1) how this White-supremacist settler colony has used education and its institutions of knowledge dissemination and reification (i.e., schooling and academia) to perpetuate itself; and (2) how peoples have resisted this through understandings of their kinship networks, of the land and space around them, and of their word-based practices (such as oral and written language use, storytelling, myth-making, mental universes based on language use) (Limes-Taylor Henderson, 2016; Limes-Taylor Henderson 2017; Limes-Taylor Henderson, 2018; Limes-Taylor Henderson, 2019); Limes-Taylor Henderson & Esposito, 2019 . While this work has led me to historical and theoretical analyses of the United States, I've only recently begun to consider what these analyses could mean in lived experience. And, perhaps more importantly, I've only begun to consider how that lived experience makes so-called marginalized<sup>1</sup> peoples feel.

Let me be even more honest, not hiding behind a "we": I've only begun to consider how that lived experience makes *me* feel.

I have lived in the United States my entire life. As a Black, queer, Muslim cis woman, I have received consistent, unabated messaging that I am inferior or unacceptable, no matter how good of a person I am, no matter what I do. While I may experience this sense of unacceptability within my own so-called marginalized groups (e.g., my knowledge that I should not be forthcoming about my sexuality in all Muslim contexts, and my feelings of alienation when in White LGBTQI spaces), this experience is greatly exacerbated when considering the deleterious effects of the dominant culture's treatment of purported minorities.

Much of my work was inspired by questions that I've asked myself while watching daily newscasts or learning about current events on social media. For example: *What does it mean that most non-Indigenous people in this country could know nothing about the epidemic of Indigenous women's murders and kidnappings happening across North America? What does it mean that the spate of police murders of Blacks is a topic for debate? What does it mean that our political leaders can be sexist, xenophobic, homophobic, and racist, yet their views are given air time and the benefit of the doubt? What does it mean if one does not have a normed-body, or a particular accent, or the documentation that permits one's existence within man-made borders?*

I've explored different answers to the question *What does it mean...?* The answers led me to theories and explanations that have helped me (and others, I hope) better understand my country. But marginalized peoples' experience with deep sadness and despair is often the unacknowledged starting point of these theories and explanations, and, by moving them into the world of theory, I believe that the sadness and despair can become disembodied. Even unreal. My understanding of this, of course, developed over time and was influenced by researchers that have spoken to this disconnect in various ways (Borland, 1991; Code, 1993; Dwyer & Jones, 2000; Fanon, 1952/2008; Hartman & Wilderson, 2003; Mills, 2007; Smith, 1999).

While this disembodiment and break from reality may be an appropriate starting point for those of us trying to understand our condition while struggling under the weight of minoritization in these lands, remaining in this state of rhetorical disembodiment actually helps the White supremacist, settler-colonialist project (Hartman, 1997; Smith, 1999; Sullivan & Tuana, 2007; Swartz, 2007; Welcome, 2004). As people historically positioned as objects in the Western settler-colonial paradigm – objects to be used or eliminated, studied or civilized – the dominant power structure has never recognized us as *minds and souls in bodies*, like normed humans are presumed to be. In other words, the U.S. settler colony has historically required the disembodiment of minoritized peoples. For those of us suffering under the larger colonialist project, then, continued disembodiment does not work for our long-term benefit, including mine. Going forward, I may write about minoritized scholars' working toward the embodiment of our peoples' experiences – including those who are currently doing the work – but, first, I need to start with myself.

Until recently, I've been working within this dominant practice of disembodiment: I could write and talk and think about the past five hundred years of Western colonialist oppression from a place of sobriety and stoicism. That is what the academy requires, after all: seriousness; the ability to talk about terrible things without getting emotional about them; the ability to move things from the realm of the heart and soul to the realm of the head. While academics have spoken and written against this requirement, it hasn't disappeared.

Not long ago, in the middle of a class, I cried in front of my class of twenty-five students. As I was explaining the importance of literacy to formerly enslaved African and African-descended peoples in the United States, I did something that I'd done in previous semesters with no problem: I drew an imitation poster of a slave auction and noted that, even if the poster was advertising my own sale, I never would have known – even if I were standing right next to it, selling/buying eggs or running whatever errand I was in town to do. I explained to the class that the written word was a code enslaved people were not permitted to access, even though it represented life or death or inexplicable loss. When I changed the sign on the "poster" to represent the sale of my children, I lost it. I started crying and could not stop. I went home feeling embarrassed and unprofessional, and though my friends and my wife assured me that my in-class breakdown was neither of those things, it did not change my feeling.

The following day, I moved from feeling ashamed of my reaction, to considering the implications of a society in which I would feel embarrassed about a natural reaction to considering a centuries-long practice that caused incalculable damage to my ancestors and my people. Why shouldn't I cry about such a tragedy – indeed, *any* tragedy – anywhere I please? Though no one accused me of being unprofessional, what does it mean that I assumed I would be viewed negatively for such a reasonable display in certain professional and/or academic spaces?

These questions, of course, stimulated different kinds of questions: *How does it feel that most non-Indigenous people in this country know nothing about the epidemic of Indigenous women's murders and kidnappings happening across North America? How does it feel to know that the spate of police murders of Blacks is a topic of debate? How does it feel to know that our political*

*leaders can be sexist, xenophobic, homophobic, and racist, yet their views are given air time and the benefit of the doubt? How does it feel to know that one who does not have a normed-body or a particular accent or certain documentation may be treated as a second-class citizen at best, a non-human at worst?*

Because the answers to these questions would obviously be some variant of “bad,” they move me further: *How does it feel to live in a society that shows you that you are inferior in a million different ways, even when you know (or try to believe) that you are not? How does it feel to live in a society that refuses to acknowledge your existence, even though you and your people are here? How does it feel to live in a society that says you are not human, though you know (or try to believe) you are?* While we can acknowledge that the types of oppression perpetuated by a dominant settler-colonial society are based on illogical assumptions about marginalized groups, at best – and preposterous assumptions, at worst – we don’t discuss what it means to live in a society whose ideological foundations defy reason. We don’t talk about how that living must feel every day. The settler colony in which I was born has to be persuaded and legislated into treating certain groups of humans as human, and into protecting clean water and trees and soil. It has to be convinced that ableism, racism, and sexism exist. When our bodies and minds are ailing or disabled, many in this colony are institutionalized, incarcerated, bankrupted, or neglected – rather than holistically treated and cared for – as if ailment and disability are aberrations of the human experience rather than common aspects of them.

This White supremacist, settler-colonial society is not just oppressive. It’s not just harmful. It’s illogical, unreasonable, untenable. It lies. Among other things, adjustment to this society requires that we accept the illogical as logical, the unreasonable as reasonable. It requires that we take lies as truth, despite being surrounded by evidence to the contrary. It requires us to assume that those who don’t care for us, in fact, want our best interest. It requires us to believe that those who fail to fit in are troubled or deficient. Or absurd. Or insane.

As this became clearer to me, I wondered about those people within the settler colonial structure who are designated as having a mental deficiency or difference, when they are actually refusing to accept (or experiencing difficulty accepting) the illogical as logical. I do not presume, of course, that different forms of mental illness or cognitive difference solely stem from dissonance

with a particular settler colonial context. Still, I wondered how this dissonance may affect the mind, and about the people whose cognitive and/or psychological difficulties are an effect of an irrational society rather than internal issue. What happens when you simply cannot assimilate the dominant narratives that excuse oppression, environmental destruction, and/or insatiable economic practice? How are you categorized or, perhaps more importantly, diagnosed? How are you treated?

I am not a mental health expert, but these last questions would not let me go.

After mulling over these questions for some weeks, I cautiously contacted my friend, Rita Sørly. Rita and I met years ago at an academic conference, and we have kept in touch since. I felt unsure about my idea, and I thought that an actual expert may not take it seriously. After all, these are the contemplations of someone deeply affected by the problem that she wants to investigate – there was no hope of the assumed objectivity or distance that the academy generally still prefers.

But Rita did take my musings seriously, and I'm grateful for it. Rita, in turn, contacted Bengt Karlsson, a professor in mental health, another act for which I am grateful. In communicating about this idea, we decided to jointly explore these ideas of mental health identity in the context of Western colonialism through the lens of our own experience. We decided to do a community autoethnography using a sequential method (Toyosaki, 2009). We allowed ourselves a slow process: sharing our individual thoughts on the topic through email, allowing ourselves weeks or even months to respond to each other's thoughts (Sørly, Karlsson and Grant, 2019). The removal of hard deadlines and other time-associated pressures allowed each of us the opportunity to reflect on our ideas while not forsaking multiple other additional demands on our time, whether in our professional and personal lives. The culmination of our explorations, this article is formatted to best convey the thoughts of each author while also highlighting the common themes that have shown up for us, despite our varied experiences.

**Bengt Karlsson: Power, knowledge, anger and me.**

First off, all I have to say is that your text is deeply moving, Kelly. I am emotionally touched by the way that you wrote about your lived experiences as part of different so-called marginalized

groups. In my evocative reading, I felt upset and angry about how these lived experiences are influencing your lived experiences as a Black, queer, Muslim cis woman in the United States. Most of all, my feeling is anger. I will try to relate to your experiences, although I am a White, heterosexual, man and socialist living in the second richest country in the world: Norway. The context from where I respond to Kelly's lived experiences is this: I have been working in the field of mental health since 1974, when I was 19 years old. I ended my clinical career in 1989 as a psychiatric nurse and started working in the academy - where I have been since. I ended my clinical work, because I experienced being involved in something that was very wrong. We were "helping" the patients by naming them as "mad" persons, doping them with medication, and giving inhumanity in many other ways.

My lived experiences as psychiatric nurse add to a long and comprehensive tradition in the mental health field. The social and historical experiences of collaborating with people with mental health issues are immensely crucial. This knowledge is important in order to understand what is at stake in understanding mental health and in the relationships between professionals and service users. Looking at the historical experiences in the mental health field, I would argue that concepts and practices such as respect, courtesy, friendliness, listening, understanding, and empathy always have been and are in play. At all times, professionals have used various "therapies" such as cold and hot baths, resting in rural areas, workout, insulin shock, electroconvulsive treatment (ECT), lobotomy and drug therapy and named this as "help" in the best sense. However, historical experiences may indicate that the desire to do the best quickly has been perceived as inhumane and suppressive by those who have been exposed to treatment. Most often, it is the professional's view of what helps and how the help is to be provided that has been decisive. The experience-based knowledge of survivors, service-users, and other 'non-professionals' is often overridden and seen as subjective nonsense.

Foucault (1967) states that Western societies have, in different times, set rules for what can be referred to as normality and deviation - and especially for what can be described as madness. This social mandate changes with the social, political, cultural and historical context in which Westerners live. The social changes are man-made. The history of psychiatry, as Foucault describes in *Madness and Civilization*, clarifies how the distinction between deviation and

normality is related to historical, cultural and social contexts. The making of this distinction is decisive in the understanding of people with mental health issues. Deegan (2000) is a psychologist having lived experiences with mental health issues and frames herself as a survivor. She states that screaming against oppression, unworthiness and inhumanity in mental health care is not reserved for patients. She emphasizes that dehumanizing practices characterized by exclusion and violations of integrity, dignity and respect are experienced by staff as much as patients. Consequently, she says that the need to cry out against oppression and opposition is equally important to professionals. Both for their own sake and for the patients - it is an expression of solidarity, compassion and respect.

The history of the mental health field shows how the society often has treated "mad people" with oppressive and inhumane methods. These historical and lived experiences can shed light on current practices. The history shows different examples of dehumanizing practices and similar attempts to constantly develop new, humanizing practices. At the same time, history shows how such changes time after time reveal our inability to look at our own practices in the same historical light. The history and current systematization of experience-based knowledge suggests that the relation between the person seeking help and the professional should actualize practices such as dignity, respect and integrity related to interpersonal cooperation and the relationship. This experience-based knowledge is both historical and current, advising us to inquire what we say and do when meeting people who experience mental health problems. Do we make a difference – meaning actual improvement – or are we merely legalizing new forms of oppression?

I will give two concrete examples of overseeing and rejecting service-users' lived experiences. The first example (Gøtzsche, 2014) refers to the absence of criticism about the scientific knowledge base of using psychotropic drugs. The author shows how patients' confidence in doctors and drugs is based on a life-threatening illusion that the drugs are safe because they have been tested and approved. In the Western world, drugs are the third most common cause of death after heart disease and cancer. Medications often lead us unexpectedly from the ash to the fire, and the patients have no foreknowledge about potential adverse effects and why they might

happen. Gøtzsche reveals how a comprehensive gambling happens to patients' lives and health, how the lie continues, even after it is revealed, in a game where profit is valued more than patients' lives. Gøtzsche asks how we have gotten to the point where we allow the pharmaceutical industry to lie about their research results for profit, commit various moral and ethical violations, and kill hundreds of thousands of patients without repercussions. In 2012, the 50 largest pharmaceutical companies sold \$610 billion in prescription drugs. Gøtzsche states that we could prevent 95% of this consumption – while simultaneously and significantly improving public health – for about \$580 billion annually.

Whitaker (2014) raises questions about how mental illness diagnoses have increased in the same period as newer psychiatric drugs have appeared on the market. He particularly asks whether these drugs are as good as the pharmaceutical industry and psychiatrists want us to believe. With this question as a background, the author reviews the modern history of psychiatry, with particular focus on research that underlies today's extensive use of psychiatric drugs. Do psychiatric drugs fix a "chemical imbalance" in the brain, or do these medicines actually create such imbalances? Researchers have examined this for decades. The answer, which already existed in the late 1980s, both amazes and shocks. For the past 50 years, researchers have investigated the long-term effects of psychiatric drugs. Did they find that these drugs were helpful for the users? Did they experience good physical health? Or did they find that these drugs, for paradoxical reasons, actually increased the likelihood that users would become chronically ill, have impaired functioning, and become more prone to mental disorders? The answers are no, no and yes. The long-term research show that people who get a schizophrenia diagnosis feel better without medication. The use of antidepressants increases the risk of depression being disabled. The results of the long-term studies, all of which point in the same direction, have been avoided publicly.

Gøtzsche and Whitaker document that the mental health field has a serious democratic problem: they note that new research and users' experience-based knowledge are not used – or not disclosed and incorporated into current practices, because it does not serve the interests of the global pharmaceutical companies. Drug manufacturers are willing to sacrifice human lives and health in favor of earning more money and increasing their profits. Imagine if a similar situation

occurred in cancer treatment or treatment of cardiovascular disorders: more specifically, imagine if drug companies concealed recent research-based knowledge of medical treatment, justifying themselves with the fact that they did not want results published for reasons of economic profit. In other areas of medical treatment and care, the practitioners emphasize the principle of using new knowledge and new research. In the field of psychiatry, however, practitioners and drug companies retain the research-based knowledge and allow neither professionals, users nor relatives to gain access to this knowledge (Whitaker, 2014).

The mental health field carries a heavy, and not particularly prudent, professional history. It is linked to an acknowledgment that providing help and security includes an ambiguity. One can give too much and too little help. The other ambiguity is linked to knowledge of what can be helpful. Historically, the professional knowledge has had a monopoly on what can help, and it has proven to be instructive and objective for the service-users. The persons with lived experiences have not had the opportunity to express their wishes and needs for help, or what they already know can be helpful for them. The latest ambiguity is linked to the fact that all "new and better" ways to provide help are justified by a pronounced desire to promote humanism, equality, and respect. However, "the new" practices quickly emerge as new dehumanizing practices. These ambiguities lead to examples of abuse, offense, and suppression of users and users' families by dominant field practices. I would argue that the mental health field has a major problem with lack of democracy – at the systemic, relational, and individual levels. Non-professionals' right to oppose or resist dominant mental health knowledge and practice is stifled, and this stifling applies not only to users and relatives, but also to professionals. Against criticism and demands for insight and openness, psychiatry meets the argument with its safest grip: silence. Efficiency is both economically and ideologically justified and results in equalization, dominance, and submission. The right and opportunity to speak, disagree, and raise one's voice is shrunk and marginalized. I see this as paradox knowing that Western politicians and leaders are travelling around the world to inform others about the values of democracy, and the importance of being democratic, humanistic, and taking human rights into account in all we do.

We need an open, transparent and inviting mental health field that can promote community solutions - solidarity and cohesion between persons with lived experiences and professionals. We

need more democracy, interaction and participation. Solidarity must be built together and from below. The health bureaucracy and the politicians can never truly develop initial involvement and participation from persons with lived experiences. Rather, it must be created locally, based on fundamental democratic values: all voices should be heard and counted equally, everyone has the right to pronounce and express himself or herself, and everyone has the right to disagree or to be wrong.

### **Rita Sørly: Throwing Pebbles**

I used to throw pebbles

up in the air

and wait for them to land

form small patterns of mosaics on the ground

between strawberries, insects and traces of childhood

memories from way back then

the smell of old rubber boots, orange juice, bumblebees stuck on the glass

long summer days

while waiting for something to happen, a friend to come, one who's gone, one that you've thought you'd like to give raspberries from the garden

the two of you would sit together

there

at the roadside to hold on

to the moment

with dirty hands and say nothing

and the pebbles would hit the ground

The mosquito would bite

and I would not wait for you anymore

I wrote this poem many years ago. I tried to become a writer, a good writer. I had so many stories inside, that I felt like I was drowning in future novels. I wrote on the bus; I wrote while making dinner; I wrote when feeling lonely or when I sat on a café, waiting for something to happen. There was always a lot of waiting. Waiting for something, very often waiting for nothing. I have never been good at waiting. From I was a little girl, my parents told me I was always in a hurry. Impatient. Moving fast. Falling often. It was often a burden for me, being so impatient. I was so impatient that even running was never fast enough; I would always come home with scratches on my knees, trying to run faster than my legs could run, stumbling in my own thoughts and feet. Throughout the years, you would believe that I learned something about waiting. But I didn't. I often scared people away in my hurry. I wanted to meet boys too fast, and, later, I wanted them to leave before they settled. I seldom had the time to wait for people to decide themselves. A lot of relations in my life are lost because of my impatience. Some of which I miss deeply, other ones which I am glad are over.

Being impatient is not always a burden; it also has its advantages. Like, I am very good at meeting people. I love meeting new people and talking with them. Actually, it might be the time where I forget about being impatient. At least, I like to think so. When I talk to people I haven't met before, I am curious. I want to know their stories, where they come from. What did your parents do, how many siblings are you, and why did you choose to come here tonight? Do you

like blue or orange, jazz or pop music? What do you think about the work of Andy Warhol or the poems of Sappho? Do you like watching jellyfish? Can you tell me your thoughts on the American election? That is a lot of questions. Maybe I still am impatient in dialogues, after all.

I have hit a wall. Working as a project leader in a study on user involvement in Sami core areas, I do not know the rules. I am not familiar with the Sami rules in social contexts, and though I don't know what I expected, it certainly wasn't this. I am read the project proposal:

*The study aims to contribute to our knowledge of what can promote increased user involvement in mental health care for Sami users with complex needs, and strengthen knowledge about involvement for service providers working within these contexts. The participants will be recruited from Sami core areas through a local manager at each community mental health center. Information letters will be distributed, and individuals who are interested in participating will sign letters of consent. The participants can bring a companion if they wish.*

It's been **several years** since I wrote the application for funding with some colleges. We got the funding. Everything was ready for exploring the mental health field in Sami areas: talking with patients and service providers, asking them about their experiences and thoughts on user involvement. But the project, as many things in life, did not work out the way I planned. It was difficult to get Sami patients to participate.

The Sami are Indigenous people living in Norway, Sweden, Finland and the Kola Peninsula in Russia. The Sami population is estimated to be about 100 000 people (Dagsvold et al., 2016). The majority of Sami people live in Norway, estimated to be around 40 000 (Statistics Norway, 2010), and around 25 000 of these speak a Sami language (Ministry of Labor and Social Affairs, Report no.55). From the mid-nineteenth century, the Sami people in Norway experienced a 100-150 year-long period of linguistic and cultural oppression and harsh assimilation policy (Dagsvold et al 2016), defined as an area of "Norwegianisation" among the Sami people. This colonization time led to the loss of Sami language, stigmatization, and discrimination (Blix et al, 2013). A Norwegian version of the White supremacist, settler- colonialist project. Kelly, relating her piece to the American context, wrote, "the dominant power structure has never recognized us

as minds and souls in bodies.” Is this, in any way, transferable to some of the difficulties I am experiencing in my Indigenous research project?

*Standardized services in Norwegian mental health care are tailored to the needs of the majority population, focusing on diagnoses and disabilities, and overshadows an approach that understands, values and emphasizes Sami thinking, values, history and everyday life.*

The project proposal was filled with good intentions. We know that culture influences the experience, expression, course and outcome of mental health distress, help-seeking and the response to health promotion, and prevention or treatment interventions (Kirmayer, 2000). Mental health care takes a unique form in each society based on its cultural history, politics and economy. Mental distress and health services reflect cultural knowledge and practice within associated systems, embedded in larger social contexts that define health and well-being (ibid.). Cultural worldviews, values, context and personhood influence how people articulate their identity through storytelling (Kirmayer, 2000, Sørly, Mathisen and Kvernmo, 2021). The interaction of social and personal narratives, drawing from cultural beliefs and practice, investigating self- presentation or social positioning within Sami contexts? What an opportunity, to grasp and understand some of these complex epistemological processes! But first, being in charge of the interviews with the Sami patients, I needed someone to participate. I knew that a central value among Sami people is to wait through bad situations, because while waiting, the situation will improve (Minde and Nymo, 2016). Did I need to wait for situations to improve?

While waiting, I went to Berlin in September, attending the Qualitative Research in Mental Health Conference. I presented our project there, while listening to well-known professors like Lawrence Kirmayer and Dainius Puras. The latter impressed me especially. Puras is a professor of medicine and comes from Lithuania. He has, throughout his career, been concerned with psychiatry and human rights. In a UN report (Puras, 2017), Puras favors that less than 7% of the world's health benefits are used for mental health, and these funds are mainly used for long-term institutional placements and psychiatric hospitals. Psychiatry has been dominated by a reductionist biomedical paradigm, and, in a global perspective, this field is characterized by human rights violations. Psychiatry must go through a paradigm shift. I agree with Puras. In a Norwegian study by researchers Nytingnes, Ruud, and Rugkåsa (2016), patients who have been

subjected to compulsion describe it as torture, depression, suppression and they have serious side effects. Patients say it feels like they live in totalitarian regimes, being imprisoned.

Who determines normalcy in our society? Is it the man-made diagnostic manuals, where doctors decide what is acceptable and not? Professor Puras raised his voice against paternalistic attitudes: "Hearing voices is a human right!" It's been a long time since I've heard something so liberating from a human being in such a position. Puras promoted mental health as a social science, rather than a medical. Mental health is about far more than medication and compulsion. "Corruption in mental health is everywhere," Puras underlined. This is also true in Norway. Everyone is educated into a biomedical understanding of mental health. Corruption occurs in the health system, in the education system, within the institutions, at the clinic, in the patient room. I know he is right. Professor Puras told many anecdotes about how he had come to his opinions. Once, he met colleagues from the Eurasia area who practiced putting people in cages at psychiatric institutions. Puras asked his colleagues what they thought about this practice, was this treatment humane? His colleagues had looked at him with astonishment and answered, "We put these people in material cages where they can physically know where the boundaries are. In the West, you put people in chemical cages. What's the worst?"

Maybe my potential participants among the Sami people have too many experiences with the cages of the majority – cages of colonialism, cages of White supremacy, cages of oppression, cages of lack of knowledge.

### **Kelly Limes Taylor: Outer limits**

Thank you so much for your words here, Bengt and Rita. To be honest, I was expecting something much different from your accounts – namely that, somewhere out there, people in some particular minoritized group (in this case, those with perceived mental health-related disabilities) would be treated with respect and dignity, careful attention would be given to their thoughts and needs, and a concerted wider effort would be made to address the societal ills that either instigate or exacerbate that group's negative experiences. Unfortunately, I saw none of that as I read your accounts. Bengt, I think it's fascinating that you left your work as a mental health

clinician because you knew you were “involved in something that was very wrong,” to the point of recognizing the “inhumanity” present in the field. Your contention that professionals’ views of “what helps” often trumps the needs of the “survivors, users or citizens” is fascinating, especially your assertion that those receiving treatment have historically understood the “help” they receive as inhumane. Rita, I think it’s illuminating that your encounter with some of the well-known names in the field echo Bengt’s assertions. I am amazed by the fact that Puras went as far as to say that the mental health field is “dominated by a reductionist biomedical paradigm” and “characterized by human rights violations.”

Both of your accounts are very telling, because I believe that they point to a hallmark of dominant Western thinking: the possibility of human supremacy. As I’ve already indicated, I am personally most familiar with notions of supremacy in specific social identifiers – race, gender, religion, and sexuality. I know what it means to be part of the “out” group – the non-“normal” ones – in each of these categories. As a person with privilege when it comes to (perceived) ability, however, I have little experience with the ways that the thoughts, needs, and experiences of anyone with a perceived disability are ignored by medical professionals, the representatives of the dominant medical institution, even when that need includes freedom from pain or feelings of physical safety. And, Bengt, as you note that some egregious acts plague the mental health field, particularly when it comes to the prioritization of pharmaceutical industry profits and relative silence around new research findings, there have also been an increasing amount of reports surfacing regarding the detrimental – sometimes even fatal – encounters between minoritized people and various areas of dominant medicine here in the U.S. It is becoming evident to me that all aspects of dominant medicine, including mental health services, could reflect this theme of dominant Western thinking, the possibility of human supremacy. In our current discussion, this theme is evinced in the mental health profession’s (and, further, the institution of medicine’s) assumptions that the professional always knows what’s best; the profession’s positioning of survivors/patients as objects perpetually available to be thought *about* and acted *upon*, but without their own thought and agency worthy of consideration; and, in Bengt’s words, the profession’s “history of constantly developing new practices” in efforts to become more humane,

without a true interrogation of the ways power and dominance determine what constitutes knowledge, harm, health, and sanity in the field.

Bengt, you mention Foucault and a lack of democracy in the field of mental health. For me, Sylvia Wynter's (2005) discussion of liminality comes to mind. In it, she references Blackness as the liminality of existence in dominant Western society, as the designation of abnormality vis-à-vis the White norm. Citing Frantz Fanon, a revolutionary thinker in the field of mental health, Wynter (2005) notes that, while dominant Western society often discusses humans in biological terms, we must also understand humans as beings who immediately and constantly conceptualize and define what it means to be human – that we are not simply “biological beings who then create culture,” but are “bioevolutionarily prepared by means of language to inscript and autoinstitute ourselves in this or that modality of the human” (p. 361). In short, we are biologically hardwired to decide who and what we are as humans – indeed, how we *do* being human. Again referencing Fanon, Wynter advises us that rather than thinking about humans in terms of ontogeny (what exists), we must think about ourselves in terms of sociogeny (what a group of humans has collectively decided about existence, especially definitions of human existence). Wynter (2005), like Fanon, asserts that, at present, we “live in a mode of sociogeny, a conception of the human, in which to be human you must be anti-Black” (p. 362). In this current mode, it is fully possible (and quite common) for Black people within Western-dominant (and even Western-influenced) societies to be anti-Black, because the “normal” human is White and because the concept of Blackness was created as a foil, the “abnormal” to the “normalcy” of Whiteness. This foil, this abnormal group, then, represents a “liminal category,” a “deviation from the norm,” which is positioned as the optimal (i.e., supreme) way of being (Wynter, 2005, p. 363). Blackness, then, represents the liminal racial category, in the sociogeny of dominant White-supremacist Western thought. But Wynter's and Fanon's assertions mean that liminal designations can and must (in a supremacist society) exist in other categories as well – in gender, class, sexuality, caste, and nationality, for example. And, of course, in ability.

Bengt and Rita, your discussions show me that the survivors/patients with which you had relationships not only represent the liminality or abnormality in dominant Western

conceptualizations of able-bodied-ness, but that there is a specific way that Western society is supposed to treat the liminal or abnormal: dehumanization. This pattern of treatment makes sense, as those in liminal designations literally fall outside of dominant Western conceptualization of what it means to be a “normal” human, and, thus, these “abnormal” humans do not have to be treated in the same ways as “normal” humans do. I’m particularly thinking of your thoughts about missing democracy here, Bengt: I don’t see it so much as a lack of democracy, but an assumption that liminal beings’ considerations aren’t even worthy of inclusion. When we understand the inhumane ways that people with the designations are treated, or the inhumane living experiences of these peoples, I believe what we’re actually acknowledging the disparities between how the “abnormal” and “normal” peoples in the applicable categories are treated, how the “abnormal” and “normal” people live. For the ways that the “normal” people live better lives is only relative to how much the liminal people live worse ones – the lives of the normal/dominant peoples are not inherently good or desirable.

And while I am not interested in an Oppression Olympics, there are, of course, implications for whether one’s minoritized social designation – and, thus, one’s abnormality or liminality – is something that is perceived as changeable or unchangeable. Some, then, can “get better” (i.e., become more “normal”) – in the categories of class or *some* disabilities, for example. Others cannot – such as in the categories of other disabilities, or sexuality, gender, or race. Even when it’s possible, the path to “getting better,” of course, is antithetical to what actually feels safe or good for us – whether it’s forgetting our languages or belief systems, engaging in physically or environmentally toxic practices, or having to submit our mind and/or bodies to institutions in order to be retrained/reformed/reformatted. Getting better is not actually getting better, then. It’s getting reprogrammed.

Rita, that brings me to the difficulty you’ve been having in connection to your work. I’m thinking of your words that mental health care takes a “unique form” in any society, and, for what little qualification I have to do so, I completely agree. I also wonder if those of us that are able to exist in Western dominant societies are *actually* mentally healthy. What must we do, psychologically speaking, to make it through the days that require our dominance or subjugation

every waking moment, whether or not we are aware of or can acknowledge it? In what ways must we disconnect from each other and the planet in order to survive? How could that disconnection possibly be healthy for us? What if there are ways of mental, physical, and emotional health that are completely unknown to us due to the seemingly-pervasive dominance of a Western system that tells us health can only mean certain things and can only present in certain ways?

When you speak of the lack of participants that you had hoped for, I am moved by your thought that, because they are aware of the different cages in which dominant society has already placed them, they may be averse to participating in your project; I infer here that you assume they are associating you and/or your institution with those historical cages. This is an honest and vulnerable thought, and I honor your willingness to share it here. It reminds me of Bengt's question: "Do we make a difference... or is another way of legalizing new forms of oppression?" Both of your musings, I believe, scratch at the surface of the painful history of systemic Western dominance and oppression within the institution/practice of medicine. It reminds me that, for many liminal peoples, Western understandings of health are not beneficial at all, but in fact seek to cut off/cut out anything that cannot be construed as normal in a society whose concept of normalcy is based on erasure, exclusion, and extinction.

When health means oppression, it is not truly health. And we should not want it.

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<sup>i</sup> Kelly Limes Taylor used "so-called" here because not everyone accepts the designations of *marginalized*, *minoritized*, etc., even if they would qualify as part of these groups.