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Madness and lived experience: An analysis of The Icarus Project

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Madness and lived experience: An analysis of The Icarus Project

Alyson Young ©

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Completed in partial fulfillment of the requirements for the Master's in Social Justice and
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Second Reader: Dr. Jennifer Root

Abstract

Psychiatric frameworks are used as the primary lens in the Western world to understand, define, describe, and categorize the experience of mental distress in individuals. The Icarus Project is a community mental health organization that has a focus on intersectionality and uses a social justice lens to look at experiences of mental distress. Members of The Icarus Project believe that they possess knowledge about the potential benefits that exist in the space between brilliance and madness as a community of individuals with lived experience of mental distress. Members believe that, through this knowledge, they can instill a sense of hope and inspiration for those who experience distress and suffering, which they argue is often due to social injustices and inequities. Using Foucaultian Discourse Analysis (FDA) this research examines four documents published by The Icarus Project. The research question for this research project is twofold. The first research question is: to what extent does The Icarus Project rely on psychiatry? The second research question is: how is “expertise” defined by The Icarus Project? How does The Icarus Project mobilize this expertise? The results from this analysis demonstrate that while the publications created by The Icarus Project use language that challenges dominant psychiatric paradigms about “mental illness” and what it means to experience emotional distress and suffering. The documents produced by The Icarus Project demonstrate the organizations effort to create space for people who accept psychiatric paradigms and those who do not. The documents reviewed for this project also demonstrate the commitment of the members of The Icarus Project’s work to create new and better healing spaces by distributing knowledge generated by people who have experience with madness themselves. Promoting the expertise of those with lived experience of madness is a central focus of the project. The Icarus Project provides an example of how people with lived experience can generate and distribute their knowledge and share it with others in similar circumstances. However, there are still opportunities for the project to increase the accessibility of the language used in their documents as well as highlight more clearly the intersection of race and distress, and to clearly articulate the project’s definition of expertise. The Icarus Project demonstrates that biomedical models of mental distress are not the only available discourse and that we can think about distress, and in turn healing, differently.

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TABLE OF CONTENTS

MADNESS AND LIVED EXPERIENCE: AN ANALYSIS OF THE ICARUS PROJECT

| | |
|--|------------------|
| ABSTRACT | I |
| ACKNOWLEDGEMENTS | II |
| TABLE OF CONTENTS | III |
| | |
| <u>INTRODUCTION</u> | <u>1</u> |
| | |
| A NOTE ABOUT LANGUAGE IN THIS STUDY | 3 |
| | |
| <u>LITERATURE REVIEW</u> | <u>5</u> |
| | |
| BIO-MEDICAL MODELS AS THE DOMINANT NARRATIVE | 5 |
| EARLY RESISTANCE: SZASZ AND FOUCAULT | 6 |
| ANTI-PSYCHIATRIC AND SURVIVOR’S MOVEMENTS | 10 |
| <i>SHIFT FROM INSTITUTIONAL TO COMMUNITY HEALTH MODELS</i> | 12 |
| MAD STUDIES | 13 |
| <i>LIVED EXPERIENCE</i> | 15 |
| THE HISTORY OF THE ICARUS PROJECT | 15 |
| | |
| <u>THEORY & METHODOLOGY</u> | <u>19</u> |
| | |
| <u>METHODS</u> | <u>23</u> |
| | |
| RESEARCH QUESTIONS | 23 |
| DATA SOURCES | 23 |
| DATA ANALYSIS | 25 |
| ETHICAL CONSIDERATIONS | 29 |
| | |
| <u>ANALYSIS</u> | <u>31</u> |
| | |
| THE ICARUS PROJECT’S RELATIONSHIP WITH PSYCHIATRY | 33 |
| <i>LANGUAGE-IN-USE</i> | 34 |
| <i>HARM REDUCTION</i> | 43 |
| <i>INFORMED CONSENT AND ACCURATE INFORMATION</i> | 44 |
| <i>SELF-DETERMINATION</i> | 45 |
| <i>NEW CULTURE</i> | 47 |
| EXPERTISE AND LIVED EXPERIENCE | 49 |
| <i>LIVED EXPERIENCE AS A FORM OF EXPERTISE</i> | 51 |
| <i>AGENCY</i> | 53 |
| <i>COMMUNITY-LEVEL SUPPORT</i> | 54 |

| | |
|-------------------|-----------|
| DISCUSSION | 56 |
| CONCLUSION | 62 |
| REFERENCES | 65 |
| APPENDIX A | 73 |

Madness and lived experience: An analysis of The Icarus Project

“We can be made ill by a diagnosis of being ill”
(Ahmed, 2017, p. 76)

Introduction

The Icarus Project is a community mental health organization that has a focus on intersectionality and uses a social justice lens to look at experiences of mental distress (The Icarus Project, n.d. “What We Do”). The Icarus Project works to create new language and culture in order to describe and support individuals who are commonly labeled as having psychiatric conditions. Members of The Icarus Project believe that they possess knowledge about the potential benefits that exist in the space between brilliance and madness as a community of individuals with lived experience of mental distress and that, through this knowledge, they can instill a sense of hope and inspiration for those who experience distress and suffering, which they argue is often due to social injustices and inequities (The Icarus Project, n.d., “Mission, Vision, & Principles”).

The Icarus Project is unique to most “mental health” programs, and is considered a “radical mental health community” because the project seeks to uncover “alternative frameworks and metaphors to understand lived experiences with mental distress” (Fletcher, 2017, p. 29). The project was created by two individuals who were categorized as “mentally ill” and continues to be operated and run by individuals who have direct experience with madness or distress. The reclaiming of the term “madness” is used by Mad movements to express the multitude of experiences individuals have had in relation to mental distress, crisis, and trauma (LeFrancois, Menzies, & Reaume, 2013). Terms such as madness and mental distress can be used to describe the varied lived experiences that people have had and allow for the creation of culture, community, and pride based on shared knowledge and understandings of mental distress. The

founders of The Icarus Project, Sascha DuBrul and Jacks McNamara, combined their passions for art, writing, grassroots organizing, social justice, and activism in 2003 to build a community of support for people who felt alienated from the mainstream psychiatric system (The Icarus Project, n.d, “History”).

The Icarus Project is named after the Greek mythological tale of a boy named Icarus (The Icarus Project, n.d, “History”). In the myth, Icarus and his father construct a pair of wings made from wax and feathers. Icarus is warned by his father not to fly too high or too low because the heat of the sun would melt the wings and the dampness of the sea would clog them. Icarus ignores these warnings and flies too close to the sun which causes his wax wings to melt and he tumbles into the sea. The Icarus Project members see madness and distress as a “double-edged blessing” noting that, similarly to Icarus, we have the potential to “fly dangerously close to the sun into realms of delusion and psychosis and crash in a blaze of fire and confusion” (The Icarus Project, “History”, n.d., para. 2) but that with experiences of madness often also comes creativity and brilliance. The Icarus Project seeks to provide new, diverse language to describe the complexity of human experience, which includes recognizing both the potential, as well as the pitfalls, of madness (as the story of Icarus demonstrates).

Using Foucaultian Discourse Analysis (FDA) this research examines four documents published by The Icarus Project which include: the *What We Do* and the *Mission, Vision, & Principles* sections of the website, a document titled *Navigating Crisis* (n.d), and a publication called *The Harm Reduction Guide to Coming off Psychiatric Drugs* (Hall, 2012). All data for this study was gathered from The Icarus Project’s website. Prior to this analysis will be a literature review documenting the historical progression of anti-psychiatry and Mad movements as resistance to the dominant biomedical narrative to describe madness or mental distress.

Following the literature review I will outline my theoretical approach which includes Michel Foucault's concepts of discourse and power/knowledge (1965) as well as Mad studies, which includes critical, intersectional, and post-colonial perspectives on madness (Morrow, 2017). This will be followed by the Methods section with details regarding the research questions, data sources, data analysis techniques, and ethical considerations. Finally, the results will be presented in the analysis and discussion sections.

A Note About Language in this Study

The language I have chosen to use to describe numerous aspects of my project has been intentional, purposefully political, and is dictated by my theoretical choices as well as my own lived experience as a mad-identified scholar. Terms such as mental illness, terminology used in specific diagnostic language, and even the phrase "mental health" all function together to reinforce the notion that objectivity lies in medicalized, binary labelling and therefore that different states of mental wellbeing are rooted in the individual body (Parker, 2015; Landry, 2017). This then implies that psychiatric knowledge is the only valid or acceptable way to know the mind. In this realm, lived bodily experience is not frequently recognized as a valuable form of knowledge, and often those who are labelled as being mentally ill are even excluded from the decision-making processes for their own treatment (Faulkner, 2017). Words matter and, furthermore, words are particularly significant when looking critically at psychiatric systems (Burstow, 2013). For this reason, I have used non-diagnostic language throughout my research.

Mad movements have focused on language as a "regime of ruling" that psychiatry enacts on individuals (Burstow, 2013). Psychiatry can wield a heavy-handed fist of authority and is the only profession able to incarcerate individuals that have not committed a crime. When we continue to use the words that psychiatry has created we are reinforcing and reproducing the

oppressions inherent within psychiatry. Bonnie Burstow (2013) outlines the work of the resisting community by demonstrating that government or medical terms such as “committal” can be replaced with resistance words such as “incarceration” which more accurately portray the lived experience of individuals (p. 83). In the same way, the government/medical term “recovery/remission” could be replaced with resistance terminology such as, “feeling better” or “acting in a way psychiatrists prefer” (p.83). Terms like mad, madness, neurodiverse (a recognition of neurological differences), creative, and crazy are considered reclaimed terminology within Mad movements in that their meaning has been recovered and co-opted by individuals with lived experience. As a result, the words we use effectively can begin to construct alternative meanings and understandings of what madness or mental distress entails. Thus, pushing back against regimes of psychiatric power involves creating space for alternate narratives, opening alternative pathways to healing, providing hope in times of despair, and placing value on non-traditional types of knowledge.

There is a large variety of resistance language and the language continues to develop on an ongoing basis. For example, rather than using diagnostic labelling, The Icarus Project employs phrases such as emotional distress, emotionally wounded, mysterious states of madness, or overwhelming suffering are used to describe the vast experiences of human emotion (DuBrul, 2014; Hall, 2012). When describing the highs and lows of mood, phrases such as altered states of consciousness, alternate realities, nonconformist beliefs, or disruptive behaviour can also be used rather than a diagnosis or disorder (for a list of language used by the project see Appendix A). Systems of psychiatry also do not take account of systemic oppression, therefore, diagnostic language does not reflect cultural differences which works to replicate racism and colonial

practices making these experiences invisible within mental health ‘conditions’ rather than calling them what they are: the impacts of oppression.

The term psy-complex is a phrase coined by Nikolas Rose (1985) which he based on Foucaultian theory that describes the interactions that occur between the human sciences, in particular: psychiatry, psychology, medicine, and criminology. The penal and medical systems are intricately linked, and both originated in “social practices of selection and exclusion” (Chambon, Irving, & Epstein, 1999, p. 85). Before the diagnostic language we use to describe madness today existed there were different labels for legal and clinical categories such as “degenerate”, which worked to categorize individuals. Rose (1985) uses the concept of the psy-complex to describe the inseparable interactions between these systems that operate specifically with the intention of regulating and understanding the mind. In this project I use the term psy-complex to refer to the ongoing connection between psychiatric and penal systems, as well as to illustrate the larger, interconnected systems of psychiatry in terms of the connection between mental health professions such as psychiatry, psychology, and social work.

Literature Review

Bio-Medical Models as the Dominant Narrative

Mental “illness” is theorized by biomedical models to be caused by “neurotransmitter dysregulation, genetic abnormalities, and defects in brain structure and function”, however, no singular biological cause or even biomarker has been determined for any mental “disorder” (Deacon, 2013, p. 847). The medical model is based on the assumption that all experiences of madness are caused by defects that are located primarily in the brain and that there is little to no difference between mental or physical diseases and, therefore, effective treatment is also assumed to be biological (Deacon, 2013). Based on the foundational notion that all mental

distress can be “cured” using biological treatments, treatments such as electroconvulsive therapy (ECT), lobotomy, and insulin coma therapy were used beginning in the 1930’s. The evolution of the theory that mental distress was caused by a chemical imbalance in the brain began in the 1950’s. As a result, the primary form of treatment for mental distress or madness became psychopharmacological drugs. However, the field of psychiatry has always precariously existed and has been labelled as a “soft science” challenging the scientific validity of the field itself. In response to this, and in order to attempt to further legitimize the field, organized psychiatry in Western society further embraced the medical model and the use of biomedical models as the foundational assumption behind treatment modalities (Deacon, 2013). This notion that all experiences of madness are the result of biologically-based brain disease continues to dominate Western medicine.

In the 1960’s, the field of psychiatry was fairly divided between biological psychiatrists and critical or radical psychologists who challenged the purely biomedical models of mental distress (Deacon, 2013; LeFrancois, Menzies, & Reaume, 2013). R.D Laing, a critical psychiatrist, suggested that experiences of madness could only truly understood by those who had directly experienced it, which he called the “politics of experience” (as cited in LeFrancois, Menzies, & Reaume, 2013, p. 5). These increasing critiques of psychiatry publicly threatened the credibility of the field and as a result, anti-psychiatric movements began to form (Deacon, 2013; LeFrancois, Menzies, & Reaume, 2013; Starkman, 2013).

Early Resistance: Szasz and Foucault

Western psychiatry has been the subject of critiques over many years that stem from different vantage points. One such distinction is the epistemological philosophies of positivist versus non-positivist ways of understanding the world (Pies, Thommi & Ghaemi, 2011).

Positivism states that we all have the ability to describe, test, and observe a measurable and objective version of reality and that this version of reality is empirical and grounded in logic and fact. In contrast to this, postmodern theorists argue that there are no universal truths, it is not possible to remain completely unbiased, and that there are no singular, objective truths but rather “there are only various perspectives or narratives that cannot be privileged as uniquely or objectively true” (Pies, Thommi & Ghaemi, 2011, p.1). This distinction is important to investigate when looking at the history of resistance to psychiatric models because, for example, Thomas Szasz forwarded a positivist critique of psychiatry while Michel Foucault explored a postmodern critique of psychiatric systems. Although neither Szasz nor Foucault considered themselves to be anti-psychiatry, both were very important in the inception of critical movements surrounding psychiatry and psychiatric systems (Bracken & Thomas, 2010).

Thomas Szasz is responsible for one of the most well-known positivist critiques of psychiatry and claimed that there is no biomedical cause for madness or distress, only what he called “problems in living” (as cited in Bracken & Thomas, 2010, p. 221). Szasz was trained and practiced as a psychiatrist, but attempted to divorce psychiatry from medicine and did not rely on medical interventions within his own practice (Gomory, Cohen, & Kirk, 2013). According to Szasz, in order for a disease to be present there must be a consistent biological/physiological cause, which is not present in the case of mental distress, therefore, he did not consider madness to be an illness or disease by medical standards (Bracken & Thomas, 2010). Szasz believed that psychoanalysis/therapy should be nonmedical and a “special type of dialogue- listening and talking” that was separate from doctors and other medical professionals (Bracken & Thomas, 2010, p. 221). Due to this, Szasz believed that if mental distress originated within individuals, it could also be cured by them by sheer force of will (Bracken & Thomas, 2010).

Szasz combined concepts from Freud and Piaget in order to develop his own theory of the origin of madness (Pies, Thommi & Ghaemi, 2011). Szasz critiqued psychiatry by comparing it to the role of the pediatrician in that the pediatrician treats the child based on the will of the parent, not the child, as children are not legally able to make decisions for themselves (Gomory, Cohen, & Kirk, 2013). In the same way, psychiatry can be viewed as using a “coercive paternalistic approach” (p. 120) because like pediatricians, psychiatrists often treat individuals who do not want their services and individuals can be treated against their will. Szasz argued strongly against this type of forced treatment. Szasz formatted his work into binary categories of distinction such as: biology vs. social science, freedom vs. coercion, and bodily illness vs. mental illness (Bracken & Thomas, 2010). Bracken and Thomas (2010) point out that these binaries within Szasz’s work are problematic because human experiences such as bereavement or grief are complex and multifaceted and cannot be understood using purely biological frameworks to attempt to understand or regulate the mind.

Szasz’s work was framed by capitalist and individualistic views about how society should function (Bracken & Thomas, 2010). He identified with free-market capitalism and believed that individuals should purchase therapy by choice, as they would any other commodity, and that psychiatric treatment should not be handled by representatives of the state. Szasz viewed the state as negative and believed that it worked to limit individual freedoms. Szasz and Foucault’s analysis of psychiatry did have some similarities in that both theorists offered a critique of institutional psychiatry as a coercive, authoritarian practice (Pies, Thommi & Ghaemi, 2011). However, Foucault’s analysis looks at medicine and science historically and at how certain notions came to be accepted as truth and how practices in society become accepted as norms (Bracken & Thomas, 2010).

In contrast to Szasz, who put a large focus on binary distinctions in his work, Foucault resisted these fundamental assumptions that informs Szasz's work. Foucault does not start his critique by creating a philosophical foundation with the intention of developing a prescriptive idea of how society should operate, but rather centered his work on what he called "*archeology*: a historical examination of how certain ideas came to be accepted as true, how certain practices came to be accepted as normal, how a certain understanding of the world came to be accepted as common sense" (Bracken & Thomas, 2010, p. 223). Foucault does not focus on whether or not madness is a biological or medical issue, as Szasz did; nor does he focus on binary issues such as questioning whether psychiatry is 'good' or 'bad'. Instead Foucault looks at how perceptions and representations of madness have changed over time in relation to the larger society that exists during particular times in history.

One of Foucault's largest contributions to analyzing psychiatric systems was his views on power and his challenge to traditional viewpoints on how power operates in society (Bracken & Thomas, 2010). Foucault did not see power as existing on a binary of positive or negative but believed that power can also be a positive and productive force. Foucault saw power as not necessarily working to suppress universal truths, but instead saw power as working to produce "regimes of truth" (p. 225) which he understood as discourses that operate in the background that create the possibility of one statement being true and another one being false. Foucault's work did not suggest that the answer or "cure" to madness lies in nonmedical interventions like psychotherapy as Szasz did, but instead Foucault saw interventions like psychotherapy as expressions of disciplinary power similar to medical interventions. He viewed the language of psychiatry as being used to label and categorize atypical behaviour and, therefore, madness as

not to be understood as matter of medical practice but instead as a form of social exclusion and control.

While many consider Szasz's work as a critique of psychiatry within the positivist tradition, Foucault critiqued both positivist and non-positivist approaches (Bracken, 1995). Foucault's critique of psychiatry does not endorse either the positivist or non-positivist tradition and he instead attempted to examine and identify assumptions present in both. In order to accomplish this Foucault analyzed the history of the human sciences and looked for the political, cultural, and social contexts within which these practices were developed. Foucault's work is used in many, but not all, anti-psychiatric or Mad movements and it is important to recognize that there is a distinction that exists between movements that have resisted psychiatry, which includes anti-psychiatric, survivor, consumer, and mad movements.

Anti-psychiatric and Survivor's movements

Anti-psychiatric movements began in the 1960's and were civil rights movements that challenged the power of the state (Chamberlin, 1995). The anti-psychiatric movement developed out of the 'Mental Patients' Liberation Movement' which can trace its roots to several streams of ideas and movements, including the gay liberation movement, antiwar and antiracist activists, and feminism (Starkman, 2013; Lewis, 2016). These social movements forwarded the notion that madness may in fact be a "sane reaction to insane social conditions [with] psychiatrists serv[ing] principally as agents of oppression" (Lewis, 2016, p. 85). For example, it wasn't until 1973 that the American Psychological Association (APA) voted to remove the diagnosis of homosexuality from the *Diagnostic and Statistical Manual of Mental Disorders*. As well, women in the late 1890's were diagnosed with "hysterical" symptoms attached to unscientific notions of

gynecology, but this type of treatment was identified as sexist by later feminist movements (Starkman, 2013).

There have also existed legacies of colonialism and racial inequalities within systems of psychiatry (Morrow, 2007; Rentmeester, 2012). Psychiatry, as one form of colonial medicine, was used to identify and measure the behaviours of groups slated for subjugation and was used to lay judgements about what was “normal” versus “abnormal”(Rentmeester, 2012). Whiteness was presumed to fall into the “normal” category which simultaneously stigmatized and othered people of colour. There were dehumanizing diagnoses developed such as “drapetomania”, defined as “the mental ‘affliction’ that ‘made’ Black/African slaves flee their owners in the United States” (Meerai, Abdillahi, & Poole, 2016, p. 22). Importantly, Meerai, Abdillahi, and Poole (2016) note the “rise and privileging...[of] white rationality [that] paints those who are Indigenous, local, and non-white as irrational, untrustworthy, and odd” (p. 24). Due to the shared experience of oppression by psychiatric systems, allegiances formed between anti-psychiatric movements and antiracist, feminist, disability, and anti-capitalist movements.

The psychiatric-survivor movement is an international movement that is made up of various organizations that work together to fight for human rights in psychiatric systems (Adame, 2014; Chamberlin, 1995; Stackman, 2013; Russo & Beresford, 2015). Individuals and groups that use the anti-psychiatric moniker have experienced oppression or abuse within psychiatric systems and have survived psychiatry itself, rather than “surviving” a particular diagnosis (Adame, 2014). There is a distinction between the anti-psychiatric survivor movement and the consumer/service user movement, mainly being that those that identify as survivors of psychiatry are explicitly anti-psychiatry and primarily reject the medical model of diagnosis and treatment; therefore, they tend to express a more radical critique of psychiatric systems.

In contrast, consumers or users of psychiatry often identify as having found psychiatric interventions helpful and see more of a role for mental health systems to intervene in experiences of mental distress. Service user movements attempt to make changes within the existing systems of psychiatry (Adame, 2014). The primary goal of the consumer/service user movement is to reduce stigma and reform current policies and procedures where the survivor movement seeks liberation from psychiatric systems by creating alternative options to psychiatry and taking legal action against forced treatment and confinement. The experience of and opposition to forced treatment and confinement is a key issue in anti-psychiatric movements. Judi Chamberlain (1995) notes that, “[s]o long as forced treatment exists, patients will continue to be angry, psychiatrists will continue to diagnose our anger as a symptom, and we shall be stuck in the same tangle” (p. 41-2).

Shift from institutional health to community health models.

Deinstitutionalization of psychiatric services began in Canada in the 1960-1980's and was executed at varying speed and intensity in each province (Sealy, 2012; Sealy & Whitehead, 2004). The term deinstitutionalization refers to the shift from custodial care in psychiatric facilities to an increase in mental health beds in local hospitals in collaboration with an increase in outpatient services available in the community (Sealy & Whitehead, 2004). Although involuntary psychiatric treatment still undoubtedly exists, (albeit in different forms such as involuntary holds and community treatment orders), this shift from institutional to community care models is one factor that has created nuanced experiences within more recent Mad movements. For example, younger individuals have experienced different forms of psychiatric authority and control in their lives, and this variance of experiences has influenced the creation of a diversity of movements (DuBrul, 2014).

Mad Studies

Mad Studies has developed out of the historical knowledge and impact of anti-psychiatric movements and questions the fundamental assumption of systems of psychiatry as the universal, empirical, objective gatekeepers of “truth” (DuBrul, 2014). Mad Studies is a recently emerging field of study that explores psychiatrization, the concept of madness, and the oppression individuals experience within psychiatric systems (LeFrancois, Menzies, & Reaume, 2013). Despite the newness of this area of study, many of these issues have previously been vocalized and resisted by activists, in the academy, and by radical practitioners, and the foundation of Mad Studies has been steadfastly built by these activists from diverse backgrounds. Mad Studies provides a platform that allows critical alternatives to psychiatric diagnosis’ or biomedical concepts of mental disorder. Using madness as a strategy for resistance demonstrates how language is imperative when it comes to using the Foucaultian concepts of discourse and the “strategic reversal of power” (as cited in LeFrancois, Menzies, & Reaume, 2013, p. 10). Thus, in a similar way to the LGBTQ community’s reclaiming of words such as queer, the reclaiming of terms such as madness, which have historically been used to oppress, begins to create a new narrative about experiences of mental distress that is dictated by people who have directly experienced it.

Recent scholarship in Mad Studies has focused on intersectionality within Mad Studies, in particular, Anti-Black Sanism. ‘Sanism’ is a term that refers to oppression experienced by people that live with mental health diagnoses’ (Meerai, Abdillahi, & Poole, 2016; Poole et al., 2012). Sanism is “a deeply embedded system of discrimination and oppression... that assumes a pathological view of madness” (LeBlanc & Kinsella, 2016, p. 59). Experiences of sanism can result in negative attitudes towards people labelled with psychiatric diagnosis’, which can result

in discrimination. Meerai, Abdillahi, and Poole (2016) coined term *Anti-black Sanism* to describe the intersection of sanism and anti-Black racism which acknowledges that sanism does not operate in the same way for all people. Experiences of sanism intersect “with class, with gender, with sexuality, with religion, and most crucial to us here, with colonization and racism” (Meerai, Abdillahi, & Poole, 2016, p. 22).

Mad Studies is defined as a “project of inquiry, knowledge production, and political action devoted to the critique and transcendence of psy-centered ways of thinking, behaving, relating and being” (LeFrancois, Menzies, & Reaume, 2013, p. 13). Mad Studies is positioned against biomedical models of psychiatric care and at the same time centers the lived experience of individuals that have experienced madness or distress (LeFrancois, Menzies, & Reaume, 2013). Mad Studies is interdisciplinary and encompasses critical scholarship from many areas of study, intentionally challenging a prescriptive or singular approach. Mad Studies takes its principle guidance and information from “those whose lives have collided with the powers of institutional psychiatry” with “Mad people and Mad culture” at the center and driving force of the study (LeFrancois, Menzies, & Reaume, 2013, p.14). Mad Studies also rejects the use of binary language such as “survivor versus consumer” movements, and recognizes the unique and nuanced experiences that exist on a vast spectrum for people engaged with systems of psychiatry. Finally, Mad Studies recognizes and values the vast history of Mad movements, anti-psychiatric, survivor, and consumer movements and provides a diverse space for the production of knowledge. The Icarus Project is a collective organization that holds similar foundational principles to Mad Studies.

Lived experience.

Experience as a form of knowledge has been forwarded in critical disability and feminist studies (Boardman, 2017; Paterson & Hughes, 1999; Voronka, 2015). Lived experience can be defined as experiential knowledge, or knowledge obtained through direct, personal experience (Boardman, 2017). The notion of lived experience as knowledge has been applied in the understanding that peer support is a “bi-directional healing process” that is mutually beneficial. The idea of lived experience and the value of peer support has been a foundational principle of Mad movements (Adame, 2014, p. 461). In mutual support models there is not a hierarchy between ‘helper’ or ‘person requiring help’, there are two individuals both deemed as ‘expert’ on their own lives via their individual experiences. Lived experience has been used in this way to “unsettle knowledge as an objective science” (Voronka, 2015, p. 60).

The History of The Icarus Project

Sascha Altman DuBrul (2014), co-founder of The Icarus Project, created the project in 2002 with the intention of challenging the dominant biomedical narrative upheld by systems of psychiatry as well as creating a supportive community for people alienated by mainstream approaches to mental distress. The members of The Icarus Project envision new language and therefore new culture surrounding experiences of madness (DuBrul, 2014; Fletcher, 2017; Mitchell-Brody, 2014). At the same time, members also recognize humans as the makers of meaning in their own lives and appreciate the gifts of creativity, inspiration, and growth that can accompany madness. They see personal narratives as an important site for experiences of creativity, struggle, and growth. Creating new narratives to discuss the diversity of psychological experiences includes seeing a rejection of the purely bio-medical, supposedly “neutral” language

of biomedical models of psychiatry. The Icarus Project sees the “power of personal narratives to challenge the power of the dominant narrative” (DuBrul, 2014, p. 258).

The project was inspired by the threads of numerous “social, political, cultural, and ecological movements” including: anarchism, anti-psychiatric movements, permaculture/sustainable ecology, LGBTQ activism, the Global Justice movement, harm reduction, counterculture, and punk rock (DuBrul, 2014, p.260). Many early members of The Icarus Project identified with the anarchist principles of direct action and mutual care and aid (DuBrul, 2014). Although they were not explicitly aware of it at first, The Icarus Project also had many commonalities with anti-psychiatric movements in the way they began to question psychiatric systems as the dominant source of knowledge of mental distress. Because members of The Icarus project tended to be younger many members were not exposed to long-term hospitalizations, there is often more diversity among members in regard to whether they accept psychiatric drugs than those involved in anti-psychiatric movements.

DuBrul (2014) and Jacks McNamara (co-founder of The Icarus Project) realized through personal experience that being involved in the growth and production of food, and interacting with the earth, helped them to manage their mental wellbeing and led to permaculture and sustainable ecology as another identifying principle of The Icarus Project. The term permaculture refers to “a set of principles for developing sustainable human systems by mimicking systems that occur in nature” (DuBrul, 2014, p.261). From this, values such as appreciating diversity and stepping back to observe patterns were integrated into The Icarus Project. Similarly, commonalities such as a focus on reclaiming marginalized language and identities as a source of pride were gleaned from LGBTQ activism, and The Icarus Project has drawn much inspiration from this movement.

Harm reduction movements typically are found in communities of drug users or people involved in sex work, and The Icarus Project holds similar values as these movements (DuBrul, 2014). The core of harm reduction principles is that all individuals have the right to have agency and decision-making abilities in their own life, which includes the care that they receive. The Icarus Project respects the individual relationships that their members have to psychiatric drugs, recreational drugs, or lifestyle choices. For example, one of the initial website forums the project hosted was titled “Give Me Lithium or Give Me Meth” which was a space for members to openly discuss the complexities of drug use.

In addition to the above influences, The Icarus Project was also created using larger principles from the Global Justice Movement, counterculture ideologies, and an essence of punk rock (DuBrul, 2014). The Global Justice Movement is a loose collection of groups that focus on transnational solidarity and co-ordinates efforts based on a critique of capitalism, grassroots organizing and activism, and education. The term “counterculture” was coined by Theodore Roszak in 1968 and refers to “the intersection of Vietnam War protestors, dropouts, and rebels of various stripes who had an effect on the larger dominant culture” (DuBrul, 2014, p. 262-3). The term counterculture also includes the Beat Generation which includes writers such as Jack Kerouac and Allen Ginsburg (DuBrul, 2014). Lastly, the critical and creative protest efforts of punk rock culture is embedded into the culture of The Icarus Project. Punk rock culture was a response to the overly sterile and conformist nature of commercial rock and roll and disco music which in turn inspired punk rock, which was essentially protest music. DuBrul (2014) notes that in the early 1990’s punk music was co-opted into mainstream culture with bands such as Green Day. This was an important lesson for The Icarus Project because it is an example of a counter

narrative being co-opted into mainstream culture and becoming a watered-down version, which all counter narratives can be vulnerable to.

Several researchers have used ethnographic methods to investigate the role of projects such as The Icarus Project as a radical mental health community. Erica Fletcher (2017) has looked at the online narratives posted by members of The Icarus Project and evaluated them as a new type of psychiatric resistance that is now possible due to technological advances and online communities and blogs. She argues that humans should not place such a significant separation between our physical bodies, our mental states, and the rest of the social world. Fletcher (2017) looks at the message board entries of two members of The Icarus Project and explores how these narratives “uncivilize” and complicate models of mental distress that are strictly biological. Fletcher (2017) defines “uncivilizing” in this context as a process of stripping away forms of thinking and searching for alternative frameworks or metaphors to help to understand the experience of extreme mental states.

Similarly, Emily Martin (2010) also used message board entries on The Icarus Project and a second message board called “alt.support.depression.medication” in order to look at brain-based explanations for human consciousness. Martin (2010) notes that how individuals engage in self-making involving the brain by collecting all references to the brain during a seven-year span on both message boards. The website alt.support.depression.medication has members that are more tolerant of medication use, as the website name suggests, whereas The Icarus Project has members that have a diverse relationship with psychiatric drugs. Martin (2010) concludes that the brain-based view of mental distress appeals to so many people in part because it relieves individuals of guilt. The assumption is that the cause of their “illness” is biological and, therefore, it isn’t something in themselves or their environment that was to blame; it wasn’t

something that they did, but rather their brain is dysfunctional. However, Martin (2010) notes that the feelings of relief that are associated with brain-based explanations for mental distress may be short-lived in the process of self-making as individuals may also feel a sense of personal responsibility for the quality, or perceived lack of quality, of their brain.

I selected The Icarus Project for this study as the organization was created, and is operated by, individuals with embodied experience of distress and madness and I was interested in the role of lived experience as a valid form of knowledge within larger psychiatric systems. The Icarus Project also sees language as an essential way to create new narratives of madness and experiences of mental distress (DuBrul, 2014; Fletcher, 2017) which correlated well with the intentions of this project. To date, no other researcher has looked specifically at the language used in The Icarus Project as an analysis of the project's positionality in relation to larger discourses of psychiatry or with respect to how expertise is defined.

Theory and Methodology

Psychiatric frameworks are used as the primary lens in the Western world to understand, define, describe, and categorize the experience of mental distress in individuals. Psychiatric systems function in a manner that has been described as medical social control, or more specifically, "therapeutic social control" (Defehr, 2016, p. 20). Therapeutic social control results from the moral and social surveillance that extends the reach of psychiatric systems throughout society. In order to critically examine The Icarus Project's relationship to dominant psychiatric frameworks as well as their understanding of what constitutes expertise, I will be using Michel Foucault's (1965, 1973-74/2006) concepts of power-knowledge and discourse, in combination with contemporary scholarship in Mad Studies, as theoretical frameworks for my project.

Foucault viewed the concept of power-knowledge as being opposing sides of the same coin in that power and knowledge are always interconnected and inseparable (1965). The concept of power-knowledge is essential to my project because institutional psychiatric knowledge is the dominant form of understanding the mind in the Western world and within this institution, individuals are designated along a binary as either sane or insane (Kendall & Wickam, 1999). Foucault's concepts of the role of regimes of power and knowledge in the creation of cultural norms is an important framing theoretical concept that I will be using to discuss how power operates within systemic structures such as the psy-complex as well as on an individual level (Foucault, 1973-74/2006).

Foucault (1973-74/2006) viewed power as not necessarily a top-down system; power is not only enacted upon people who have experienced mental distress in an oppressive manner by systems of psychiatry, but also, Foucault draws our attention to a system where everyone at every level participates in the reproduction of power-knowledge, which then becomes continuously reinforced and reenacted. This process works to create social norms. The internalization of these social norms can in turn become an exercise of control where we, as subjects, both regulate ourselves in accordance with social norms and are regulated by larger systems such as the psy-complex (Foucault, 1973-74/2006; Rabinow & Rose, 2003). As members of society, we have all internalized the expectation to perform as "good" and "sane" citizens and therefore are engaged in continuous evaluations by others and ourselves for evidence of our "normality" (Rabinow & Rose, 2003). The mind is categorized in the psy-complex as existing on a binary: it is either ordered or disordered, sane or insane, labelled as having a diagnosis or labelled as "typical". There are a number of problems with categorizing the mind in this way, for example, the fact that it does not leave room for human experiences outside

of the binaries created by biomedical models alone and does not provide space for experiences such as grief, trauma, and violence (Deacon, 2013; Tietze, 2015).

Foucault's concept of discourse is important both theoretically and methodologically to my project. Connected to his concept of power, Foucault sees discourse as a way of speaking about, describing, and defining the social world (Kendall & Wickam, 1999). Foucault considered discourse productive, as in discourses can "produce things" or bring subjects into being. For example, "medical discourses about 'folly' and 'unreason' produce the mentally ill person" (Kendall & Wickam, 1999, p. 34). Foucault's concept of discourse will be useful for me in order to take a critical stance to investigate the socially constructed understandings of madness. Foucault's notion of discourse is also particularly important to Mad Studies because the discipline strives to articulate the non-dominant discourse around mental wellbeing and to challenge the way the dominant discourses discuss and understand mental distress.

Mental wellbeing cannot simply be categorized as having only biological and psychological causes, there are also social factors that impact mental wellbeing that have often been dismissed or ignored by the traditional psy-complex including experiences of marginalization and oppression (Morrow, 2007; LeFrancois, Menzies, & Reaume, 2013). Thus, the primary difference between the approach taken by Mad Studies as compared to psychiatric systems rooted in biology is that psychiatric interventions are primarily focused on diagnostic labelling and drug therapy (Morrow, 2007). Psychiatry does not respond in any significant way to the evidence that "mental distress is intimately tied to social inequities like poverty, homelessness, racism, homophobia, and sexism" which is a foundational assumption that informs Mad Studies (Morrow, 2007, p. 73).

Mad Studies follows in the Foucaultian tradition of being concerned with “critical pedagogy – in the radical co-production, circulation, and consumption of knowledge... as a strategy for contesting regimes of truth” (as cited in LeFrancois, Menzies, & Reame, 2013, p. 14). I will be using Mad Studies, which in many ways is an extension on Foucault’s work, as a second theoretical framework for my project. Specifically, Mad Studies will enable me to better analyze how traditional systems of psychiatry have claimed to possess infallible knowledge of the mind and have become the primary way of understanding mental distress, yet it has been documented that psychiatry also has a sordid history of abuse, most prominently against women, Indigenous communities, and LGBTQ people (Morrow, 2017; Bonisteel & Green, 2005; Marriner, 2012).

Mad Studies incorporates a post-colonial and intersectional approach that seeks to understand madness and mental distress by critically analyzing the psychiatric system and by valuing the lived experience of people who have knowledge of mental distress. Morrow (2017) posits that within psychiatry the biomedical model and neoliberalism are intertwined in that they both actively promote focus on the individual and do not include the role of societal, cultural, and historical impacts on mental distress. Mad Studies is a useful framework for my project due to its resistance of the binary narrative (ie., that ‘madness is bad and sanity is good’) and allowing space for the stories of collective movements of people with lived experience of mental distress, while also articulating a variety of opinions on the positivity or negativity of neurodiversity. In sum, Mad Studies views mental distress as an often-normal response to the unjust and oppressive world around us.

Methods

Research Questions

The research question for this research project is twofold. The first research question is: to what extent does The Icarus Project rely on psychiatry? The second research question is: how is “expertise” defined by The Icarus Project? How does The Icarus Project mobilize this expertise?

Data Sources

The data used in this project was publicly available on The Icarus Project Website, <https://theicarusproject.net/>. I first looked at two areas of The Icarus Project website, the *Mission, Vision, & Principles* and *What We Do* sections. The *Mission, Vision, and Principles* section of their website (<https://theicarusproject.net/mission-vision-principles/>) helped me to understand the core principles that make up and construct The Icarus Project. This section of the website was two pages in length. I also looked at the *What We Do* section of the website (<https://theicarusproject.net/what-we-do/>) which provided me with foundational information about the specific types of work that The Icarus Project has done in the community. This document was also two pages long. I chose the *Mission, Vision, and Principles* and *What We Do* sections in order to investigate how the language that the Icarus Project uses to describe themselves reflects the organizations view on psychiatry. I was interested in whether or not the project referred to psychiatry explicitly in these sections of their website which outline the core principles surrounding how and why they do their work.

In addition, I analyzed the *Harm Reduction Guide to Coming off Psychiatric Drugs* which was 52 pages long and was published by The Icarus Project and the Freedom Center in 2012 (<https://theicarusproject.net/resources/publications/harm-reduction-guide-to-coming-off->

[psychiatric-drugs-and-withdrawal/](#)). The Freedom Center is an advocacy and support organization run by individuals labelled as having “severe mental disorders” (Freedom Centre, n.d., “Welcome”). They advocate for “compassion, human rights, self-determination, and holistic options” as well as alternatives to traditional psychiatric systems. The Harm Reduction Guide to Coming off Psychiatric Drugs was authored by Will Hall (2012), co-founder of The Freedom Center. The *Harm Reduction Guide to Coming off Psychiatric Drugs* is intended to provide honest information about psychiatric drugs and broaden the discussion surrounding them for those who choose to take psychiatric drugs as well as for those who seek to reduce or stop taking psychiatric drugs. The guide acknowledges that many people do find psychiatric drugs helpful and choose to take them despite the risks, which is a personal choice based on individual circumstance. However, the guide also provides information about the dangers and harms associated with psychiatric medication and guidance for those who choose to reduce or stop taking psychiatric drugs in order to provide readers with data and guidance that is not readily available.

I also examined the two-page pamphlet available on The Icarus Project website called *Navigating Crisis* (n.d) which is a printable handout published by The Icarus Project (<https://theicarusproject.net/resources/publications/handouts/>). This handout provides advice and instruction for those who experience mental distress and for those who support individuals who experience mental distress. I chose these two resources, which are primarily meant for consumption by psychiatric survivors and their supporters, because I wanted to understand who The Icarus Projects considered experts about responding to mental distress and how this expertise is used to support individuals experiencing distress. In total, I looked at 58 pages of text data from The Icarus Project’s website.

Data Analysis

For this project, I used critical discourse analysis in the Foucaultian tradition to analyze how The Icarus Project talks about mental distress because I was interested in the way that The Icarus Project has created a counter-narrative to knowledge generated within the psy-complex. I was also interested in how The Icarus Project defines “expertise” within their organizational structure and how they in turn utilize this expertise. I chose discourse analysis because this approach focuses on language, and words are extremely important within Mad movements. I chose Foucaultian discourse analysis in particular to assist me with critically analyzing the power of the words used to label individuals within psy-complexes and to consider how society positions psychiatry as the sole and dominant way to know the mind (Chambon, Irving, & Epstein, 1999; Kendall & Wickam, 1999; Burstow, 2013). Mad studies and Foucaultian theory challenge the notion that systems of psychiatry are the sole way to understand experiences of madness by directing focus towards both what is stated within the data as well as situating this specific data in the larger social discourse that the data belongs to.

I used coding to qualitatively analyze the data I collected from The Icarus Project. Coding can be defined as a manner of sorting, organizing, and linking data in order to consolidate and categorize it and then connect it back to themes and concepts for analysis (Saldaña, 2013; Braun & Clarke, 2006). I followed the six suggested phases of thematic analysis that Braun and Clarke (2006) recommend which begins with becoming immersed in the data. To accomplish this, I read the data I collected from The Icarus Project fully several times while making notes about my initial observations and ideas for preliminary codes. Saldaña (2013) states that “coding is a cyclical act” (p. 8) so I also interacted with my data in a cyclical manner which involved several stages of coding. I used manual coding method where I used different

coloured pens to review and code the data (Braun & Clarke, 2006). I also used the computer word search function to supplement my manual coding. I created preliminary codes (Saldaña, 2013) as I thought of them while I analyzed the data. The preliminary codes for my project were: *psychiatrist*, *psychologist*, specific diagnostic language (from the Diagnostic and Statistical Manual of Mental Disorders), and refusal or resistance language (such as: *mad*, *crazy*, and *creative*). My preliminary codes were intentionally broad, and as I interacted further with the data, I narrowed my codes and began to look for themes.

After I immersed myself in the corpus, I created a list of initial codes that connected back to my research question (Braun & Clarke, 2006). I broadened the medical language to include codes such as: *biology*, *doctor*, *illness*, *brain chemistry*, and *mental health*, to capture more information on The Icarus Project's perspective on psychiatry. I also added codes such as *media* and *science* and began to look in to the authorship of the different documents in order to investigate The Icarus Project's perspective on expertise. I used these initial codes to review my data again in a systematic manner and noted examples in the data that were relevant to each code. Because my project looks at lived experience as a form of knowledge, it is important to use methods of analysis that supports flexibility and can "provide a rich and detailed, yet complex, account of data" (Braun & Clarke, 2006, p. 78). I therefore used a constructionist method to examine how realities, experiences, and meanings are understood as a result of a variety of discourses operating at once within society (Braun & Clarke, 2006). In the next phase of analysis, I remained open to shifting or adjusting my codes depending on the information I was gathering from the data. I also began to sort codes into general themes and look for patterns in the data (Saldaña, 2013). The initial themes I created were: culture, agency, language, community, and expertise.

In the next phase of my research, I reviewed and refined the themes in order to confirm their relevance to the overall data set as well as at the level of individual codes (Braun & Clarke, 2006). I did this by creating a visual thematic map of my main themes as well as the layers of codes that have made up the themes which assisted me in determining if my data was manageably diverse and to see if there were any themes that could be combined or separated. I combined several themes at this time and moved culture into a sub-theme for discussion. Once I had created sufficient visual maps of the themes present in my data, I began to narrow down and hone in on specific themes, determining how these themes relate back to my research question (Braun & Clarke, 2006). The themes language-in-use, harm reduction, informed consent and accurate information, self-determination, and new culture connect back to the first component of my research question which looks at The Icarus Project's reliance on psychiatry. The themes agency, lived experience, and community are connected to The Icarus Project's perspective on expertise. Next, I began to analyze each theme in detail and identify any sub-themes that were present. The sub-themes I produced were: refusal/resistance language and diagnostic language, new culture, self-determination, informed consent/accurate information, harm reduction, communal support/collective experience, difference.

It was also important to consider who authored the individual documents and when in order to determine their relevance or authority to provide information about The Icarus Project's goals. I noted the dates of the documents as well as individual authors when this information was available. I then looked at how the discursive constructions I identified fit into wider discourses about psychiatry. In *Madness and Civilization*, Foucault (1965) notes that the language of psychology is a "monologue of reason about madness, has been established only on the basis of

such a silence” (p. x-xi). Foucaultian discourse analysis then looks not at just the history of language, but also the “archeology of silence” (p. x).

I used Foucaultian Discourse Analysis (FDA) to look at the ways in which “discursive objects” are constructed within the texts I have identified from The Icarus Project (Willig, 2008, p. 384). Reading text for discursive objects goes further than reading for just key words because both implicit and explicit references are included. FDA looks at “language-in-use” which assumes that “...language constitutes rather than reflects reality, and that speakers use talk strategically to accomplish their purposes in particular settings” (Miller, 2000, p. 317). Therefore, language is both political and moral, not objectively empirical, and FDA challenges the notion of our ability to locate a singular, universal Truth (Miller, 2000). Health, and in particular ‘psychological health’, can be a moral discourse, and as a result the body and mind can be “a site for moral action” (Conrad, 1994, p. 385).

At this stage, I began to look at the intertextuality of the five Icarus Project texts I have selected as data. Intertextuality refers to the process of relating one text to another in “the endless referentiality of texts and other elements of cultural production” (Fox, 1997, p. 32). The concept of intertextuality is important for my project because I was looking to situate the documents as they related to each other as well as to larger discourses (Willig, 2008; Fairclough, 2008). The next stage of my analysis included looking at the relationship in the texts between discourse and practice, which involved identifying the types of potential practices that are opened up for people within the subject position produced by The Icarus Project.

Finally, I have written up the analysis of my findings to provide an account of the story that the language used by The Icarus Project tells and how this connected to my research question. This approach was connected to my decision to use Foucaultian and Mad Studies

theoretical frameworks for my project because I was interested in looking at both what is, and is not discussed, regarding psychiatry and how this reflects the larger discourse about madness and mental distress.

Ethical Considerations

Although I was not required to seek permission through the Research and Ethics Board as I used entirely public data published by The Icarus Project, there are still a number of ethical implications for The Icarus Project that I have considered during all stages of constructing my Major Research Project. Tuck and Yang (2014) discuss the experiences of communities of “overstudied Others” within the larger academic industrial complex and point out that ethical standards for social science research do not ensure that research is truly “ethical, meaningful, or useful to the individual or community being researched” (p. 223). There is often a tendency to focus on “a pain narrative” which places emphasis on the documentation of damage or attempting to “empirically substantiat[e]... oppression and pain” (p.226). This damage-centric viewpoint within research relies on a theory of change that subscribes to the belief that damage and harm must be proven and held to a particular threshold or standard in order to convince or persuade others that reparations are required. Tuck and Yang (2014) conclude that the Academy’s fascination with mining for pain narratives, particularly from communities that are not White, wealthy, straight, or for the purpose of this project, sane, is not helpful to these communities and can be damaging and harmful as it leaves particular communities with a “narrative that tells them that they are broken” (p. 227).

The psychiatric-survivor movement has been deeply affected by the increase in the commodification of personal stories being mobilized for use in capitalist marketplaces (Costa, Voronka, Landry, Reid, McFarlane, Reville, & Church, 2012). In the same way that Yang and

Tuck (2014) describe the pain narrative as being used to reproduce feelings of alterity, psychiatric survivors have had their pain harnessed and manipulated for profit by larger psychocomplexes. Costa et al. (2012) refer to this use of lived experience for profit as “disability tourism” or “patient porn” (p.85). In this work, the use of the word “porn” reflects a process in which one person is in the position of revealing deep, intimate, personal information, which typically describes a painful fall and then a path to recovery, and other people are then in the position to receive “passive relief from watching, while still others profit from the collaboration of those on the front lines in compromised positions” (Costa, et al., 2012, p.86).

Personal stories have become commodified in the market as capitalist societies begin to recognize the disruption to productivity that mental distress causes as well as the potential profits that lie in the pharmaceutical industry (Costa et al., 2012). People who have experienced mental distress are often paid a small honorarium (or nothing at all) in order to have their stories twisted, edited, and paraded, and to display their pain in front of politicians, board members, nurses, doctors, community members, funders, and donors, in order to reinforce the message that the only path to healing lies within psychiatric industries, and that with individual hard work one can be “cured” (Costa, et al., 2012, p.89). This neoliberal narrative completely excludes the wider social justice issues present within experiences of mental distress such as racism, poverty, sexism, and violence. In this same way, Guthrie (1976) states that the roots of psychology can be traced back to efforts to “scientifically prove the supremacy of the White mind” (as cited in Tuck & Yang, 2014). Just as anti-colonial, racialized, disabled, Indigenous, and queer scholars have worked towards reclaiming or refusing specific types of research, the psychiatric survivor movement has also fought to reclaim their worth and dignity by dictating how these stories are told, when and why they are told, and whom they are told to (Costa et al., 2012).

Due to this historical and current dilemma of the commodification of pain, within my project I continuously reflected on the vulnerability of The Icarus Project and of others that possess lived experience of mental distress. I did this by using the reflections of Costa et al. (2012) and Tuck and Yang (2014) by refusing to reproduce pain narratives for no productive purpose. Conversely, this also includes refusing to sanitize painful stories that were told, which is preferred by the psy-complex and the Academy in many ways (Costa et al., 2012). This sanitization of pain often involves the retelling of some components of a story, as well as the researcher picking and choosing the “relevant” pieces of the story, which in essence diminishes individuals by reducing them to the value of their story, and as having no other worth outside of their pain. In contrast, when I appropriate I attempted to retell the full story of the examples I used, rather than to segment and utilize only the painful portions. These ethical considerations were integral to the completion of a project on madness that embodied social justice principles.

As well, throughout my project I was compelled to continuously acknowledge and draw attention to the fact that those who experience mental distress exist on a spectrum, as do treatment modalities and strategies. Experiences of mental distress are not one-size-fits-all and, therefore, consideration should be given to individual experiences and components of distress. It was my intention with this project to look at alternatives to traditional psychiatric models of care, but not to come up with prescriptive solutions that will work for everyone. My intention instead was to open up a pathway of communication that places value and recognition on the voices of those directly impacted by experiences of mental distress.

Analysis

Each of the documents that I have selected as data for this project were directly authored and published by members of The Icarus Project, including the Who We Are, Mission, Vision,

and Principles, and the Navigating Crisis document. All of these documents are hosted on The Icarus Project's website (<https://TheIcarusProject.net>). The Harm Reduction Guide to Coming off Psychiatric Drugs (shortened to HRG for the remainder of this document) is also hosted on their website, was co-published by The Icarus Project and The Freedom Center, and was primarily authored by Will Hall (2012). Will Hall has a Masters degree in Process Work, or Process Oriented Psychology as it is referred to in Europe, and is a counselor, trainer, writer, and community development organizer (willhall.net). Hall's work and learning emerged due to his own experiences with hearing voices and madness. He co-founded The Freedom Center and was a former co-ordinator and a long-term organizer at The Icarus Project (willhall.net).

Although HRG was not directly authored by current members of The Icarus Project, the project has hosted the guide on their website since 2007 and Icarus co-founder Sascha DuBrul (2014) speaks of the document directly when he says, "The Icarus Project embraced the spirit of the harm reduction movement in its publishing of the Harm Reduction Guide to Coming off Psychiatric Drugs (Hall, 2012), which gathered the best information and valuable lessons we could find about reducing and coming off psychiatric medication" (p. 262). While the authorship of the HRG (2012) may not directly be by current members of The Icarus Project, it is clear that they are supportive of the content within the guide and considered the information valuable to the community because they have both published the guide and posted it on The Icarus Project website. As a result, I have included this document in the data set and will give similar weight to the HRG as I do the other documents authored directly by The Icarus Project.

The research questions guiding this project focused on the relationship between The Icarus Project and psychiatry, as well as how The Icarus Project defines and mobilizes expertise within their work. Using a critical discourse analysis, the following eight key themes were

identified: language-in-use, harm reduction, informed consent/accurate information, new culture, and self-determination, lived experience, agency, and community-level support. Each of these themes are discussed in more detail below, as they relate to the research questions.

The Icarus Project's Relationship with Psychiatry

I wanted to investigate the Icarus Project's connection to larger psychiatric discourses in order to explore how The Icarus Project (a collective of individuals with lived experience with mental distress) talked about and interacted with psychiatric systems, while at the same time generating and distributing knowledge based on lived experience rather than professionalized knowledge. The Icarus Project has varying iterations of their perspectives on the psy-complex; perspectives which have changed and evolved over time. At times, such as in the HRG (2012), the publications produced by The Icarus Project members are quite explicit about their perspectives on psychiatry. For example, in the Author's Note (p. 5), Hall (2012) iterates his personal experience with psychiatric institutions and labels. Hall (2012) describes having experienced serious suffering and being told that this suffering was caused by biological causes. Hall (2012) was prescribed psychiatric medication which helped him for a while, but after he engaged in his own research, he determined that psychiatric medication was one option among many, rather than the only option. Another example of The Icarus Project's perspective on psychiatry is in the section of the HRG (2012), *Looking Critically at "Mental Disorders" and Psychiatry* (p. 10). The title of this section relays the message that The Icarus Project members have a critical perspective on psychiatric systems, meaning that they reject many of the key assumptions of psychiatry.

The evidence that points to The Icarus Project's non-reliance on psychiatric principles includes the language that is used in the projects publications and website and the promotion of the principles of harm reduction, informed consent, and self-determination. These combined aspects work to create a new culture which offers diverse language to describe the complexity of human experience as well as new and different behaviours and actions based on this language, which in turn creates new available actions to support people experiencing mental distress or suffering. The following sections discuss in more detail how The Icarus Project creates new culture through language and actions.

Language-in-use

The Icarus Project envisions a new culture and language based on the lived experience of suffering and distress (DuBrul, 2014). Discourse analysts have noted the significance of language because the "...words we use to describe our experiences play a part in the constitution of the meanings that we attribute to such experiences. Language has a constructive dimension; it does not simply mirror reality" (Willig, 2008, p. 56). The language that The Icarus Project used in the early days of the organization reflects the founders' activist roots and experiences with grassroots organizing, which often led to an outright and explicit rejection of psychiatry, but this position has continued to progress with the growth and evolution of the project (for a list of language used by The Icarus Project, see Appendix A). Thus, although The Icarus Project shares many of its roots with anti-psychiatric movements, the members of the project also soon realized that there was a wide variation of experiences and ways that it's members identify in terms of their personal relationships with psychiatry and psychiatric labels, and therefore not everyone in The Icarus Project community outright rejected psychiatry (DuBrul, 2014).

For example, in an article co-founder Sascha DuBrul (2014) wrote summarizing the evolution of the project, which included descriptions of the mission, vision, and principle statements from 2005, the mission statement for The Icarus Project refers to mental distress as “dangerous gifts requiring cultivation and care, rather than diseases or disorder” (p. 266). This mission statement clearly indicates their position on biomedical models through the renaming of their experiences and rejection of dominant discourses by stating that they do not believe that madness or distress should be categorized as diseases or disorders. Foucault (1973-74/2006) notes that to “say someone was mad, to ascribe madness to him, was always to say that he was mistaken, and to say in what respect, on what point, in what way, and within what limits... madness was basically characterized by it’s system of belief” (p. 7). The Icarus Project echoes this Foucaultian conception of madness by the ascertain that mental distress and suffering should not be categorized as disorders. Further the mission states that “The Icarus Project helps us overcome alienation and tap into the true potential that lies between brilliance and madness” (p. 266) which demonstrates the projects perspective that experiences of madness do not exist on a binary of “good” or “bad” and that they are advocating for a spectrum to describe experiences of extreme emotion or distress using language.

Similarly, DuBrul (2014) states the vision of The Icarus Project in 2005 which again explicitly states their relationship to psychiatry by maintaining that “[t]ogether, we seek new space and freedom for extreme states of consciousness. We support alternatives to the medical model and acknowledge the traumatic legacy of psychiatric abuse” (p. 267). The Icarus Project states this position on psychiatry clearly but also notes that, as a community, they welcome everyone, “whether they support the use of psychiatric drugs or not and whether they identify with diagnostic categories or not” (p. 267).

Finally, DuBrul (2014) recounts the eight guiding principles from 2005: Beyond the medical model, educating ourselves about alternatives, balancing wellness and action, access, non-judgement and respect for diversity, a non-hierarchical organizational structure, and anti-oppression, nonviolence, and transparency (p. 267-268). In terms of the project's relationship to psychiatry, the first principle clearly states that The Icarus Project looks beyond biomedical models of knowing the mind, and the second principle explicitly positions the project as promoting alternatives to this model. Furthermore, The Icarus Project refers to these as both principles and values of their organization, which guides and supports the work that they do.

In contrast to 2005, the mission statement in 2018 is shorter and the Project's positionality on psychiatry is less explicit:

The Icarus Project is a support network and education project by and for people who experience the world in ways that are often diagnosed as mental illness. We advance social justice by fostering mutual aid practices that reconnect healing and collective liberation. We transform ourselves through transforming the world around us (Para. 1).

While The Icarus Project does not explicitly state their position on psychiatry in the 2018 mission statement, the language they use still generally reflects their resistance to biomedical models by stating that "people who experience the world in ways often diagnosed as mental illness" rather than using diagnostic labels (such as bipolar or schizophrenic) which are based on biomedical assumptions about the mind and distress. The Icarus Project also forwards the idea that collective forms of aid and healing, such as the online peer support group that they host (The Icarus Project, n.d., "What We Do"), are needed rather than an individualized response to treat an individual "problem" located in one's body, which are the solutions relied upon by psychiatric

and biomedical approaches. Moreover, The Icarus Project articulates in their 2018 mission statement that they intend to “transform the world around us”. Thus, in the 2018 vision statement, The Icarus Project forefronts the notion that the world needs changing, rather than individuals summarizing this idea in the following quotation: “[a]s a mutual aid community, we intertwine threads of madness and creativity to inspire hope and transformation in an oppressive and damaged world” (Para.2).

In 2018, The Icarus Project lists five principles (instead of the eight principles in 2005) on their website which they also call their values: self-determination, respect and responsibility, educating ourselves and others, balancing wellness and action, and social justice (The Icarus Project, n.d, “Mission, Vision, & Principles”). There is some continuity in The Icarus Project principles and values between 2005 and 2018, such as balancing wellness and action. However, other categories were more fundamentally changed, like access and anti-oppression, which were combined and expanded upon in the social justice section. The social justice section (2018) articulates their position on psychiatric systems, and this is when they acknowledge the intersecting oppressions that cause individuals mental harm such as the “ongoing legacies of abuse, colonization, racism, homophobia, transphobia, ableism, sexism, and other interlocking forms of oppression” and then the next statement is that, “mental health and health care systems reproduce oppression” (para.5). The principle of social justice highlights the project’s understanding of the role of psy-disciplines in the pathologizing and medicalizing of marginalized groups; however, they do not fully unpack their assumptions and leave unexplained what the reproduction of oppression actually looks like in mental health systems. It is important to note that there are other documents on The Icarus Project’s website that appear to further articulate these ideas, and more clearly define their understandings of social justice, however

these were not part of the data set in the current project. While generally rejecting psychiatry as a framework, in both the 2005 and 2018 documents The Icarus Project does maintain that anyone with lived experience is welcome to access the Icarus Project community, whether they use diagnostic language or not, and whether they take psychiatric medication or not.

While there is not any specific information in the data about the reasons for the shift from an explicit rejection of psychiatry in 2005 to a more “neutral” stance on the role of psychiatry (or at least one that does not explicitly reject psychiatry), this change may be strategically advantageous for The Icarus Project because it creates room and allows for individual’s different relationships to psychiatry without them feeling blamed or at fault for relying on this system. Language is key in creating this type of room. In the 2018 vision statement, the importance of language is explicitly outlined in the statement: “We aim to create a language that is so vast and rich that it expresses the infinite diversity of human experiences” (para. 1). By providing alternative language to medical discourses, the members of The Icarus Project work to create space for “exploring different states of being” (para. 1) which provides options outside of the pathology and labelling of normal human behaviour.

In sum, the data shows that, over time, there has been a significant change in the language that The Icarus Project uses to talk about psychiatry. More specifically, in the 2005 mission statement and principles, The Icarus Project’s relationship with psychiatry is clear: they are positioned in opposition to reductionist or solely biomedical models and they also believe that there are alternatives to this system. The Icarus Project is one such alternative. In 2018, the vision statement on The Icarus Project website echoes many of the same themes, but this time their relationship with psychiatry is much less explicitly challenged than in the 2005 vision

statement when they state: “sensitivities, vision, and inspirations are not necessarily symptoms of illness, they are gifts needing cultivation and care” (para. 2).

When looking to other documents for evidence of The Icarus Project’s use of language as an indication of the projects positioning in relation to psychiatry, there is support for the idea that The Icarus Project rejects many, if not most, of the assumptions made by biomedical understandings of mental distress but that they simultaneously work to make their alternatives to psychiatric systems accessible to as many people as possible, which includes those that do accept psychiatric labels and treatments. This is brought to the surface in the Navigating Crisis (n.d) document in section 8 where it reads: “Calling the police or hospital shouldn’t be the automatic response” (p. 2). This specific section outlines the complexity that exists between law enforcement and hospitals/medical treatment, and how this impacts access to psychiatric services. The document suggests being realistic about when medical intervention is required and encourages individuals to think about the amount of support they are capable of providing. The Navigating Crisis document also suggests being cautious about diagnoses people receive with statements such as: “labels can be helpful, but madness is ultimately mysterious, and diagnoses aren’t scientific or objective” and “having a disease label is not the only way to take someone seriously and get help” (p. 2). The Navigating Crisis (n.d) document has the phrases “authorities” and “mental illness” in quotations likely to mark their challenge to the use of these phrases, and to indicate that they don’t necessarily accept police/hospitals as authorities, and that the project questions the use of mental illness to describe people’s experiences of distress. Thus, the Navigating Crisis document uses diagnostic language when needed such as the use of the term “mental illness”, but if these terms are used, they are always challenged by using resistance language as well.

The Icarus Project documents highlight the project's focus on the importance of the use of diverse language to describe distress which opens the door for individuals to begin describing their experiences in new ways. For example, in the following statement from the Navigating Crisis (n.d) document: "in the medical establishment's opinion, *mental illness* is a highly deadly disease. Whether or not you choose to see things this way, the stark fact remains that the *extremes of mood swings* have driven people to suicide" (p. 2, emphasis added). The author of the document makes certain to note that the term "mental illness" is the "medical establishment's" term and the author then reframes this idea in the next sentence by replacing the term 'mental illness' with 'extremes of mood swings'. The Icarus Project uses both biomedical descriptions ('mental illness') and resistance terminology ('extremes of mood swings') which allows both individuals who identify with psychiatric labels, and those who do not, to understand and identify with the project.

The Icarus Project documents also use both diagnostic language and refusal/resistance language to challenge dominant paradigms about "mental illness". When diagnostic language (ie: bipolar, depression, schizophrenia) are used in Icarus Project documents, it is almost always countered by resistance or refusal language (ie: mad, creative, brilliant). By laying out their documents this way, the members of the project are actively challenging the dominant, medicalized language of psychiatry. In *Madness and Civilization* (1965) Foucault argued that the labelling and diagnostic processes that were developed within the psy-complex worked to produce "mental illness" by labelling some behaviours as normal and others as abnormal and requiring treatment. The Icarus Project demonstrates resistance to this diagnostic labelling. For example, the HRG (2012) includes a section called "*Looking Critically at 'Mental Disorders' and Psychiatry*" (p. 10). In this section, Hall (2012) describes how the belief that mental distress

is due to biological *causes* is different than biological *factors* (such as diet, sleep, and allergies) being related to mental experiences of wellness or distress. Hall (2012) suggests that relying on the premise that distress is due to biological causes (such as a “chemical imbalance of the brain”) leads to the assumption that psychiatric medication is the only option. Hall (2012) challenges this idea by designating psychiatric drugs as one option, rather than the only option, which can be understood as generally mirroring the relationship The Icarus Project has with psychiatry and psychiatric drugs.

Another example is in the opening statement of the HRG (2012) which states that: “doctors put people on psychiatric medications for experiences labeled ‘mental disorders’, extreme emotional distress, overwhelming suffering, wild mood swings, unusual beliefs, disruptive behaviors, and mysterious states of madness” (p. 10). This statement supports The Icarus Project’s use of language to resist biomedical and diagnostic labeling by creating new, diverse language to describe the complexity of human experience. Medical anthropologists note that it is important to understand the role of language in “constituting and maintaining social order and notions of reality” (Lupton, 2004, p. 19). The next statement in the section uses language in a different way: “Currently millions of people world-wide...take psychiatric drugs when they are diagnosed with bipolar disorder, schizophrenia, psychosis, depression, anxiety, attention deficit, obsessive-compulsive, or post-traumatic stress” (2012, p. 10). This statement, which closely followed the first, uses medicalized language to describe madness which makes The Icarus Project accessible to individuals that do identify with diagnostic labels as well as those who do not identify that way.

Similarly, the Navigating Crisis document (n.d) authored by The Icarus Project uses both diagnostic and resistance language. This document opens by describing behaviours that a person

may exhibit if they are experiencing a crisis such as personality changes, sleeping all the time or not at all, losing contact with the people in their lives, and dwelling on suicide or hopelessness (p. 1). This is in opposition to using labelling or diagnostic language to describe crisis, which could look like defining crisis as only suicidal behaviour (which can be a crisis but is not present in every crisis) or referring to it as a “mental health crisis”. Moreover, a key aspect of this reframing is that anyone can experience a crisis, whether they have been given a diagnostic label or not. The Navigating Crisis (n.d) document defines crisis in order to again counter diagnostic language and present new options of resistance or refusal language to use in place of medicalized terms.

By giving new language to describe mental distress, The Icarus Project works towards their vision of creating new culture, as is demonstrated in the following quote from the HRG: “Studies show that trying to convince people that ‘mental illness is an illness like any other’ is a counterproductive strategy that actually contributes to negative attitudes” (Hall, 2012, p. 23). Placing mental “health” on a binary of illness versus wellness works to perpetuate the idea that the sole cause of distress and mental “unwellness” resides in the individual body, as biomedical models conclude (Poole et al., 2012). However, the language that most people must use to describe their experience is determined by biomedical models because alternatives have not been readily available. By challenging the idea that mental distress is caused by an “illness” The Icarus Project is opening the door to providing people with new language to describe their experiences that is not based on biomedical paradigms.

Harm Reduction

The second key theme that was discovered about The Icarus Project's relationship to psychiatry is harm reduction. Harm reduction is an international movement that recognizes that there is no universal treatment that works for every person and that getting "rid" of "problem behaviour" is not always the only acceptable form of treatment (The Harm Reduction Guide to Coming off Psychiatric Drugs, p. 7). Harm reduction approaches to mental distress or substance use work to meet individuals where they are at, and to provide treatment options that reduce risk and increase wellness and overall quality of life. These approaches are centered in the lived experiences of sex workers, drug users, and other "criminalized communities" (DuBrul, 2014, p. 262). Harm reduction principles challenge the traditional Western discourse of the doctor-patient relationship (which include psychiatric approaches) by focusing on the needs and desires of the individual. The principles of harm reduction also contest the assumption that certain individuals are 'less-worthy' of care, concern, and the treatment or medical intervention that they desire for themselves. The philosophy of harm reduction places the individual in the driver's seat of their lives, and the professionals in supporting roles.

Harm reduction principles are woven throughout The Icarus Project documents from the Mission, Vision, and Principles, the content of the HRG (Hall, 2012), to the promotion of Advance Directives in the Navigating Crisis (n.d) document. The following excerpt from the HRG (2012) demonstrates this commitment to nonjudgmental and individualized approaches to supporting people experiencing mental distress: "People need help not judgement" (p.7). While harm reduction is most known in the realm of substance use, The Icarus Project utilizes the same tools in the context of madness. Making decisions based on harm reduction principles then becomes a "process of experimentation and learning, including learning from your own mistakes

and changing your goals along the way. Harm reduction accepts all this, believing that the essence of any healthy life is the capacity to be empowered” (HRG, 2012, p. 7). Utilizing harm reduction principles in treatment planning involves individuals making choices based on personal need and preference as well as looking honestly at all the risks and rewards of a decision or treatment option to “reduce risk and increase wellness” (HRG, 2012, p. 7). The HRG (2012) notes that practicing harm reduction relies on the individual receiving accurate information about the treatment options available to them, as well as informed consent about what happens to them.

Informed Consent and Accurate Information

An important and connected principle to harm reduction is informed consent and providing accurate information to individuals about treatment planning, options, and alternatives. Informed consent is a medical principle where individuals are to be informed fully of the proposed treatment plan and are empowered to have any questions they have about the risks or benefits answered (College of Nurses of Ontario, 2017). However, as noted in the data, patients are not always fully informed of risks and potential harmful side effects of psychiatric medications (The Harm Reduction Guide to Coming off Psychiatric Drugs, 2012, p. 20). A key goal of The Icarus Project is to advocate for relevant, up-to-date, information and research from pharmaceutical companies, medical practitioners, and the media so that the principle of informed consent can actually be realized (HRG, 2012). The Mission, Vision, and Principles (2018) document states that The Icarus Project “...research[es] medical treatments, learn all that we can about their risks and benefits, and respect the role that personal beliefs and intuition play in decision-making” (p.2).

Informed consent is also an integral component of many of the other themes that were discovered in the data including self-determination and harm reduction. In order for a person to be able to make important decisions in their lives, they need to have a complete understanding of the treatment plan, including any risks or benefits. The HRG (2012) notes that “[i]n this complicated environment, people are looking for accurate information about risks and benefits, so they can make their own decisions” (p. 11). Thus, a key message of The Icarus Project is the belief that when a person is fully informed with accurate and up-to-date information, they can then weigh out their options and decide what risks they are or are not willing to take when it comes to treatment options.

Self-Determination

The Icarus Project centres practices of self-determination which includes providing space for people to use whatever language they feel comfortable with to describe their experiences with madness or distress, and respecting how they choose to navigate their experience (The Icarus Project, Mission, Vision, & Principles). The HRG (2012) is also guided by the following principle of choice and self-determination: “We have the right to self-determination: to define our experiences as we want, seek out practitioners we trust, and discontinue treatments that aren’t working for us” (p. 13). This is often in direct contrast to a biomedical approach. When individuals access (voluntarily or involuntarily) psychiatric systems, they are often told that their “mental illness” is due to something being wrong with them individually and that this is primarily due to biological causes (Krücke, 2007). Often there is also an assumption that these individuals are not able to make “good” or “rational” choices for themselves because of the biological problem (Leblanc & Kinsella, 2016). As a result, those who experience mental distress are expected to rely on the expertise of others, primarily psychiatrists, to make decisions to about

their treatment. Therefore, according to Foucault, the medical encounter is a function of disciplinary power and the body becomes both the “target and effect of power” (Lupton, 2004, p. 120). As power according to Foucault is not necessarily always oppressive, but is also productive, then within the medical interaction the patient and doctor can also collude to solve the problem of illness (Lupton, 2004). A collaborative process between doctor and patient creates self-determination in individuals seeking care because power is also a productive process which “creates human subjects and their capacity to act” (Petersen & Bunton, 1997, p. 35).

Another example of self-determination is psychiatric advance directives, which are legal documents that are meant to protect the rights of individuals to make decisions regarding what health care intervention they do, or do not, want (Ambrosini & Crocker, 2007; Ziegler, 2007). These directives allow individuals to proactively outline what their choices and preferences would be in a crisis situation or other future events in a “legally meaningful manner” (Krücke, 2007, p. 97). The sample advance directive included in the Navigating Crisis (n.d) document was written by Mary Ellen Copeland, PhD, based on her own lived experience (Ziegler, 2007). This example advance directive asks the individual first to “describe [themselves] when they are well” and moves next into asking for a description of what it may look like if they are no longer able to make decisions for themselves and a list of what people should be involved in their care (p. 4). Next, the individual is asked to list their “preferred medications and why” and “unacceptable medications and why” and which treatment facilities are acceptable, and which are not (p. 4). Advance directives are an action that The Icarus Project is promoting that creates a different culture around madness and distress because it encourages individuals to act in advance and write down specifically what actions, medications, or treatments an individual is comfortable with. As a result, pathways are opened to new ways to treat people experiencing distress that

forefronts the principles of self-determination and challenges the dominance of the psychiatric and biomedical models. Individuals with lived experience of mental distress have described advance directives as some “confirmation that my problem is indeed not a medical one” (Krücke, 2007, p. 103).

New Culture

The 2018 vision of The Icarus Project includes their desire to create new culture allowing for the “space and freedom for exploring different states of being and recognizes that breakdown can be the entrance to breakthrough” (para. 2). Culture can be defined as a group that shares a set of beliefs and related behaviours, and members of this group use these to create meaning in their social environments (American Sociological Association, n.d). In the case of The Icarus Project, members of the project are working to create a new shared set of beliefs related to understanding “different states of being”, which are reflected by the language that they use that challenges dominant psychiatric frameworks and, along with this, new behaviours to enact the new culture that they have imagined. Thus, the use of new language is one of the key factors involved in making a new culture, and has already been discussed in detail. In addition, The Icarus Project also encourages a number of new behaviours and actions. Advance directives are one example of this. Other examples include members of the project publishing documents for use in both self-care and community care, such as Navigating Crisis (n.d) and The HRG (Hall, 2012). Both the Navigating Crisis document and the HRG (2012) include sections specifically discussing how to provide care to others and includes suggestions such as to work in teams. The document also points out that those who experience distress are often very isolated and require support (Navigating Crisis, n.d) and sections in the HRG include sections about cultivating support and what to do if you think someone else is overmedicated (Hall, 2012).

Additionally, The Icarus Project facilitates workshops and trainings for peers, which include holding healing spaces and collective conversations about emotional wellness with an anti-oppressive analysis. More specifically, the anti-oppressive analysis that informs these workshops and trainings includes an understanding that the “ongoing legacies of abuse, colonization, racism, homophobia, transphobia, ableism, sexism, and other interlocking forms of oppression” and that “the mental health and health care systems reproduce oppression” (“Mission, Vision, & Principles”, para. 8). The Icarus Project also provides trainings and talks for service providers where members of the project are able to share their collective experience of navigating mental health systems. This is an opportunity to bridge their lived experience with those who work in therapeutic roles in order to fulfill a key objective of The Icarus Project which is to “create better healing spaces” (“What We Do”, para. 3) as opposed to curing people of mental illness, which is a primary goal of a biomedically informed psychiatric framework. The Icarus Project also organizes rapid response webinars that are designed to help train community members in emotional safety specifically for organizational use. The subjects of these webinars range from topics such as *Street Therapy: Emotional Resistance in Action* and *Healing Legacies: A Panel on Intergenerational Trauma*. The Icarus Project notes that this content is not made available to support specific individuals, and they do not provide individual or group counselling, but rather develop peer-created tools aimed at the level of communities which help to facilitate communities to build up their own capacity.

In terms of the project’s relationship to psychiatry, the focus that The Icarus Project places on community and collective care directly opposes biomedical and psychiatric models which emphasize the need for individual change and the responsibility for that change lying as being almost entirely on the individual themselves (Jones & Pietilä, 2018; Marriner, 2012).

Instead, The Icarus Project provides supports for collective healing and community care. Thus, while The Icarus Project may not have an explicit position about psychiatry currently stated on their website, the language and principles that the project promotes in their publications including harm reduction, informed consent and accurate information, self-determination, and a new culture in relation to mental distress, implicitly demonstrate their position on psychiatry and psychiatric systems. In sum, The Icarus Project has a critical stance on psychiatry in that their documents question purely biological causes of mental distress and provide alternative language, causes, and treatments for distress.

Expertise and Lived Experience

The second component of my research question examines how The Icarus Project defines expertise and how they mobilize that expertise within the context of the project. More generally, the concept of expertise is not easily defined, is highly contested, and often exists in a “generative loop of expert power” that is self-perpetuating meaning that those who are already considered “expert” are often the ones who determine who else has this status (Marriner, 2012, p. 114). Anyone outside of this closed loop can be dismissed as “not understanding” due to their non-expert status, which results in a form of protection against challenges to experts. Moreover, different types of knowledge are granted different levels of power (Faulkner, 2017). Within psychiatric systems, knowledge that is considered to be “professional” (which is often identified through some form of education/accreditation) is given more status than knowledge gained through lived experience, and the vast majority of mental health research in Canada does not involve people with lived experience beyond their role as “research subject” (Landry, 2017, p. 1439). More specifically, stigma and stereotypes about people who have been labelled with

psychiatric diagnoses is that mad people are not capable of rational thought (Leblanc & Kinsella, 2016), and therefore the knowledge they possess is often, if not always, devalued.

However, it is also interesting to note that the delineation between “professionals” that have knowledge based on education and credentials and those who have lived experience is not clean cut. In a study on service provider lived experience of mental distress and stigma, 75% of respondents reported some degree of personal experience with mental distress or madness (Harris, Leskela, & Hoffman-Konn, 2016). Yet, even though this study suggests that a majority of service providers have both professional and personal knowledge of madness and distress, there is a professional culture in place that dissuades service providers from discussing their own past or present mental health concerns. The perpetuation of stigma amongst mental health service providers is a documented concern. This stigma could prevent mental health professionals from seeking help themselves should they experience mental suffering or distress. Similarly, in academia, there is an under-representation of employees who report disabilities, chronic conditions, or neurodiversity which also may be partly due to under-disclosure and stigma (Brown & Leigh, 2018). As well, when the knowledge generated by lived experience is used in a meaningful way, it is often co-opted or used with political motivations within the psy-complex, particularly the co-option of the stories of mad-identified individuals (Landry, 2017; Russo & Beresford, 2015; Costa et al., 2012). For example, the psychiatric system often uses the personal stories of individuals who have experienced distress or madness to increase research, education, and fundraising prospects (Costa et. al., 2012).

Although The Icarus Project documents that I reviewed do not explicitly define expertise, I was able to find several key components that provide insight into what they consider expertise

and that indicate how members of The Icarus Project feel this knowledge should be mobilized. These key components include: lived experience, agency, and community-level support.

Lived Experience as a Form of Expertise

As has been discussed previously, the dominant way Western society understands madness and distress is through biomedical discourses produced within the psy-complex (Leblanc & Kinsella, 2016). This has resulted in the perspectives of people who have experienced madness or distress being excluded in mainstream discourses. The Icarus Project interrupts these discourses by producing documents that emphasize and value the creation and distribution of the knowledge and experience of mad-identified people. Lived experience refers to experiential knowledge or “knowledge gained through ‘embodied’ (direct bodily experience) ...of a phenomenon” (Boardman, 2017, p. 186). Many definitions of lived experience, including the definition used here by Boardman (2017) include “empathetic experience” which is defined as proximate experience by a person close to an individual, such as friends or family. The definition of lived experience in this project refers specifically to the embodied experience of individuals. Similar to the Icarus Project, disability rights, feminist, and mad movements have all advocated for increasing the value placed on knowledge gained through lived experience (Boardman, 2017).

The Icarus Project prioritizes lived experience by promoting and publishing materials created by people who have experience with madness, such as the HRG (2012) and the inclusion of Advance Directives in the Navigating Crisis document (n.d). In addition, in the Author’s Note of the HRG (2012), it states that the guide is an attempt to collect the most valuable information and lessons learned by the members of The Freedom Centre and Icarus Project. Hall (2012) goes

on to say that the HRG is not perfect and he welcomes the reader to contribute to future editions of the project (p. 5) which positions the document as a “living document” that allows for progression and change based on the embodied experience of others. In this way, the documents authored by mad-identified people associated with The Icarus Project work to push back against typical ways of generating knowledge about madness.

Lived experience being expressed in professional settings is often described as “peer support” work. Peer support is recommended as a valid type of care six times in the HRG (Hall, 2012), including a statement in the medical disclaimer which reads, “This guide is written in the spirit of mutual aid and peer support” (p. 2). In The Icarus Project’s “What We Do” section, it notes that workshops and trainings are specifically intended for peers, that they offer online peer support spaces, and also that the tools they offer are “peer created and community sourced” (para. 5). Lived experience can also be defined as the “constantly shifting realm of every day experiences” which then can become experiential knowledge, defined as “the ordered and re-countable version(s) of that lived experience” (Boardman, 2017, p.191). Using this definition, peer support can then be understood as an expression of this experiential knowledge gained from embodied experience.

Peer support models are recognized as a useful form of social support within biomedical frameworks, although peer support workers are often viewed as sharing common experiences and providing emotional care (Jones & Pietilä, 2018), rather than as individuals with “expertise”. Despite this, recent research has demonstrated that the roles of peer support workers goes far beyond providing emotional support, and includes “expertise, advocacy, and activism as central features of their work” (Jones & Pietilä, 2018, p. 1). Jones’ and Pietilä’s (2018) study looked at the role of volunteer peer support workers in Finland and found that peer support workers should

aim to challenge the notion that they do not possess legitimate knowledge and authority because peer supporters were found to be doing much more complex work than only providing emotional support. Similarly, The Icarus Project's documents are, in essence, a way to mobilize and distribute experiential "peer" expertise.

Agency

While expertise is most often defined as residing with "professionals", as an organization The Icarus Project promotes principles of harm reduction and self-determination which instead locates expertise as residing in the individual as the ruler of their own life. Agency is defined within the current study as an individual's ability to navigate and make decisions in one's own life with an understanding that individuals ultimately are only able to make constrained choices based on their life circumstances (Hill, Collins, & Bilge, 2016; Rentmeester, 2012). The phrase 'constrained choices' refers to a model created by Chloe Bird and Patricia Rieker (2008) which states that there are factors that affect the opportunities that individuals have to make choices about their own lives, which includes decisions and actions at the family, community, and government levels.

The Icarus Project outlines the importance of the concept of agency in the Mission, Vision, and Principles (2018) that guide their work, in the principles that outline The Harm Reduction Guide to Coming off Psychiatric Drugs (Hall, 2012), and in the promotion of Advance Directives in the Navigating Crisis document (n.d). The recognition that it is beneficial to give agency and choice to individuals experiencing distress or suffering, and that this contributes to healing, comes directly from the knowledge of those with lived experience of both being supported and of supporting others. Historically there has been a dependence on biomedical

models to provide answers or solutions to social and medical problems, which has created the “mythology of the beneficent, god-like physician” (Lupton, 2004, p. 1). It must be recognized that the culture a patient exists in effects individuals experience of “illness”. Given that The Icarus Project documents universally recognize the importance of agency, it is clear that members of the project instead position expertise as residing within the individual as the primary decision-maker in their own life.

Community-level Support

One of the running graphics through The Icarus Project documents and website is a drawing of birds surrounded by a circle of words that says, “You are not alone” (Hall, 2012; Navigating Crisis, n.d). The Icarus Project recognizes that overcoming alienation and isolation is key to survival and healing, and is used to “help each other stay balanced and grounded so we can use our insights to make the world we live in better, more beautiful, and way more interesting” (“Mission, Vision, & Principles”, para. 7). The Icarus Project’s focus on community widens and enhances the discussion about how to best care for others who are experiencing distress, and about where this knowledge is located.

For example, the Navigating Crisis (n.d) document uses a practical, step-by-step approach to describes how to support a person experiencing crisis on a community, rather than individual, level. Steps include: work in teams, try not to panic, be real about what’s going on, listen without judgement, lack of sleep or drugs can be a major factor in crisis, create a sanctuary, and calling police or hospital should not be an automatic response. Responses based solely on biomedical paradigms typically offer a very different pathway to support. For example, the Canadian Mental Health Association (CMHA) Ontario’s website lists the following options

on the “Are you in crisis?” webpage (n.d): contact your doctor, go to the nearest hospital, find a crisis line or mobile crisis response team, or call 9-1-1 or Telehealth Ontario. Every suggested response on the CMHA Ontario (n.d) website recommends a medicalized response to crisis. This approach locates the cause of distress in individual bodies, which are often defined as “out of control” or “irrational” and thus requiring intervention by authoritative experts located within systems such as psychiatry and medicine. In direct contrast to this approach, The Icarus Project’s production of the Navigating Crisis document uses the collective knowledge of those who have had similar experiences of distress to provide a fundamentally different understanding of what it means to support a person experiencing distress or madness. This approach is based on locating expertise outside of “professional” support. By highlighting the role of communal support in the Navigating Crisis (n.d) members of The Icarus Project work to forward the notion that if, as suggested, mental distress is not an individual ‘problem’ or ‘deficiency’ that resides in individual bodies, it would then only make sense that their approach to healing would also be on a community level.

In conclusion, although The Icarus Project documents examined for this project do not explicitly define expertise, there are indications of the organizations perspective on expertise. The Icarus Project promotes lived experience as a valid and legitimate form of knowing. The project promotes principles such as harm reduction and self-determination which advocate for individual agency. Finally, The Icarus Project mobilizes their expertise gained through lived experience by collecting the information that their community has produced and making it as available as possible to others by publishing it on their website free of charge.

Discussion

The analysis in this project has determined that The Icarus Project does not rely on psychiatry as the sole authority in diagnosing and addressing mental distress and madness, but also works to not explicitly reject psychiatric ways of knowing if that is how people prefer to understand their experience. This approach echoes the foundational principles of Mad Studies, which presents critical alternatives to psychiatric diagnosis and has a diverse understanding of psychiatric systems that includes an intersectional analysis of madness and distress. The Icarus Project also provides an example of how people with lived experience of madness can generate and distribute the knowledge they have learned and share it with others in similar situations. As part of this goal, the project puts significant efforts into being as accessible as possible, and this is to be commended. However, based on my in-depth analysis of certain documents, I observed that there are still opportunities to increase accessibility further so even more individuals are able to understand the alternatives that exist to challenge psychiatric systems. My suggestions include: to closely examine the accessibility of the language used in their publications, to continue to account for the complexity and difference in experiences of diverse communities with a focus on people of colour and Indigenous communities, and to more clearly articulate their perspective on expertise.

The documents used for this research project included a significant amount of language that may not be particularly accessible to people who have not had access to higher education. While this set of documents certainly did not include everything The Icarus Project has written, it did include key documents that would likely be some of the first texts that people new to the project would read. For example, in the 2018 Mission, Vision, and Principles under Principle 5: Social Justice, it states:

We recognize that we all live in a crazy world and that too many of us struggle due to ongoing legacies of abuse, colonization, racism, homophobia, transphobia, ableism, sexism, and other interlocking forms of oppression. We also know that mental health and mental health care reproduce oppression (para. 5).

The terminology used in the principles are not defined in the documents examined for this project. Therefore, for a person that was new to these concepts and was accessing these documents as a starting point may not have a full understanding of what the project means by this statement or terms such as colonization, ableism, or oppression, without a clear definition of the terms being included. While not included within the data set, it is important to note that The Icarus Project does make a number of attempts on their website to make these concepts more accessible, such as the video *Sea Change: Navigating Oppression*, available on the Online Support page (<https://theicarusproject.net/resources/online-support/>) as well as another publication called *Madness & Oppression* (2015). The video explains interpersonal, institutional, and cultural oppression in plain language as well as internalized oppression, and describes the psychological distress and harm caused by experiencing oppression. The *Madness & Oppression* (2015) document provides further definitions of terminology such as: oppression, patriarchy, sexism, and colonialism. Definitions of key terms such as these throughout all of The Icarus Project's documents would help the publications to be more accessible to all individuals who are interested in alternatives to psychiatric systems (Grace, 2013). Using plain language to describe complex theories allows more people to access and understand the intent of The Icarus Project. If the language is inaccessible it may prevent individuals doing further research into the project.

Secondly, the Navigating Crisis (n.d) document has a bolded section above Section 8 that states: "Police and hospitals are not saviors. They can even make things worse" (p. 2). The

document goes on to explain that “when you are out of options, though, you shouldn’t rule them out” (p. 2). However, what is not addressed in this statement about police intervention in mental distress is that different populations can experience varying effects of madness intersecting in their lives along with race, class, gender, or sexual orientation (Tam, 2013) which includes interactions between people experiencing mental distress and police or other authorities. By making the statement in *Navigating Crisis* (n.d) that the police are “not saviours” and “can even make things worse” this document does not fully capture the reality that lethal state violence that impacts some individuals more than others. Psychiatric systems embody systems of norms that operate as a form of social control that significantly impacts racialized, Indigenous, disabled, immigrant, queer and trans people (Spade, 2011). The effect of this is that certain people’s life chances are better than others due to systemic injustice. In the same way, people experiencing mental distress are often seen as dangerous rather than needing protection or care (Knaak, Mantler, & Szeto, 2017), and this is especially the case for people of colour who are experiencing distress. An example of this is the case of Sammy Yatim, a racialized 18-year old man who was not formally diagnosed or diagnostically labelled as “ill” but displayed symptoms of mental distress on a bus in Toronto (Gillis, 2018). Yatim was shot nine times by police, three of which were after he was already deceased, after no attempt was made at de-escalation. This case makes clear that due to racism, racialized individuals face higher risk of lethal violence than others when experiencing mental distress and being intervened upon by police and similar agents of the state, like the psychiatric system.

In her book *Policing Black Lives: State Violence in Canada from Slavery to the Present*, Robyn Maynard (2017) draws attention to the state-sanctioned surveillance, control, and punishment of Black communities in Canada. Black people with mental health issues are often

treated as if their lives have less value or that they are disposable, compounding this suffering (Meerai, Abdillahi, & Poole, 2016). Maynard (2017) also points out that Indigenous and Black communities have many shared struggles, specifically around state violence. We must account for this disparity in the chances that Black and Indigenous individuals who experience distress will be intervened upon with violence by representatives of the state rather than care and support in order to begin to address systematic inequities that are built into current psychiatric systems.

There is also the alternative, but related, concern that persons in distress who *do* want to access services through the hospital or other state-sponsored systems may not be able to access these resources even when they request it. A recent example of this occurred when an individual of the Frog Lake First Nation in Alberta, put a video on Facebook pleading for assistance accessing emergency psychiatric services (Bell, 2018). The individual described feeling at risk to himself and had attended numerous hospitals requesting assistance and was not admitted. The person pleaded for help on Facebook saying, “I’m scared that I’ll die” and “This is a cry to the world, like for whoever will listen, whoever can help me. I’m not mentally stable right now. I don’t feel good and I need help”. It was only after his video was viewed over 230,000 times and shared more than 5,000 times that he was admitted to Ponoka Hospital. He recently updated Facebook that he is doing a bit better now that he is receiving help in the hospital that he had been desperately asking for. This is particularly concerning as the message that many people who are suffering receive is that they need to just “reach out for help”, but no one talks about what happens after you reach out and find there is no help available.

Being able to access health services when needed is an important determinant in overall health (NCCAH, 2011). Not all Canadians, however, have equal access to health services and Indigenous peoples face significant disparities in accessing appropriate treatments across

Canada. Barriers to treatment include geographic, socio-economic, and cultural obstacles to accessing health services (p. 2). For example, the individual in the example above lives in a Northern community in Alberta, which may be one of the key barriers he faced while attempting to access the care he needed. Recent studies have demonstrated that life expectancy rates for people who live in Northern Ontario are lower than the rates in the rest of the province (Health Quality Ontario, 2016). Access to health services can be negatively impacted by an individual's socio-economic status, their geographic location, a lack of local infrastructure and staffing, and language or cultural barriers (NCCAH, 2011). Despite the fact that access to health services has been forwarded as a social issue, there is still significant progress yet to be made, as is evidenced by the experience of the man from Frog Lake, Alberta. There is value in The Icarus Project continuing to work to centre the most marginalized of voices, which is one of the stated principles of the project ("Mission, Vision, & Principles", 2018). Mad movements have been critiqued previously for being "inadvertently white spaces" (Meerai et al., 2016, p. 27), therefore, it is imperative to continue to highlight where experiences of madness and racism intersect.

Finally, despite the promotion of lived experience as a valid form of knowledge generation, The Icarus Project does not explicitly define expertise and thus does not end up addressing the overlap that exists between professional knowledge and knowledge generated through experience. The documents produced by The Icarus Project forward knowledge gained from the lived experience of many members of the project, but the documents do not include any information on the same members academic or professional knowledge. This creates the question: what is knowledge gained by lived experience? Can it include knowledge gained from mentorship, professional, or academic experiences? Does academic knowledge somehow negate lived experience? An example of this is located in the HRG (2012) which includes supplemental

resources including published scientific studies and there is a list of “Health Professional Advisors” that supported the publication (p. 51). It is made clear that these advisors are “not co-authors [but are] experienced with helping people come off psychiatric drugs” (p. 51). The list of professional advisors includes 36 people that possess graduate degrees. Furthermore, author of the HRG (2012), Will Hall, has a Masters Degree and is currently a PhD candidate at Maastricht University Medical Centre- School for Mental Health and Neuroscience (willhall.net/about). Similarly, Sascha DuBrul, co-founder of The Icarus Project also recently obtained a Masters Degree in Social Work and now works as a Recovery Specialist for a mental health program for young adults (DuBrul, n.d). While DuBrul has stepped back from his role at The Icarus Project, and he obtained his credentials after the inception and creation of The Icarus Project, this blending of lived experience, along with academic credentials and professionalization creates a challenge for understanding what “expertise” is within the context of The Icarus Project. Given that a core goal of The Icarus Project is to challenge dominant psychiatric (and thus professionalized) discourses, this lack of clarity surrounding the blending of different forms of expertise may lessen the impact of the project’s stated focus on lived experience.

In order to continue to promote the value of the addition of lived experience as a form of knowledge within a dominant discursive framework, which disproportionately places value on credentials and professionalization, it would be beneficial for The Icarus Project to more clearly articulate the complexity that exists within the definition “lived experience”. By placing emphasis on the value of lived experience without identifying that mad people are in fact also professionals, academics, peer support workers and hold various forms of expertise, their presence is invisibilized as agents of expertise that are present within psychiatric systems. By not defining expertise clearly there could be a negative impact on understanding lived experience as

expertise. By engaging in a more complex discussion of what it means to utilize lived experience as a form of expertise, The Icarus Project could potentially help to combat stigma within psychiatric systems on a much larger scale, and also challenge the myth that ‘professionals’ are not capable of possessing lived experience of distress and still remaining a rationale ‘professional’.

Conclusion

The Icarus Project members work to construct a different narrative about madness and distress by advocating for principles such as harm reduction and self-determination, which promote individual autonomy and decision-making. Language is key in creating this type of room. This is compared to the biomedical model which locates expertise in the doctor or professional as the only “credible opinion” while deeming the patient themselves un-credible (Marriner, 2012). The Icarus Project also uses vast, detailed, and mostly non-diagnostic language to explain experiences of madness or distress, which works to create a new culture and new understanding of what it means to be mad. By providing alternative language to medical discourses, the members of The Icarus Project work to create space for “exploring different states of being” (“Vision”, para. 1) which provides options outside of the pathology and labelling of normal human behaviour.

My selection of The Icarus Project was intentional as I was seeking a site to study where the many valid and valuable threads of resistance and recovery alternatives to traditional biomedical models of psychiatry existed simultaneously. The Icarus Project both accepts and acknowledges the experiences of individuals that hold various perspectives and positions on the spectrum of madness/creativity/mental wellness and by doing this they have carved out a middle

ground in approaches where people with similar experiences can gather as a collective (DuBrul, 2014). There have always been counter-narratives to dominant psychiatric systems which are created by people that are labelled or designated as mad by systems of psychiatry (Russo & Beresford, 2015). Instead of unequal power relationships that disadvantage and oppress people who experience madness, creating space for these differing narratives will work to help individuals feel less alienated. Further research may continue to investigate the complexity of “lived experience” in that individuals may possess many types of experience, including embodied, professional, and academic. As well, continuing to examine the intersectional experiences of madness with a specific focus on racism and the experiences of racialized and Indigenous communities is imperative as “mad spaces are often inadvertently white spaces” (Meerai, Abdilahi, & Poole, 2016, p.27). Systems of psychiatry are not staffed by individuals who are immune to the diversity of human experience and suffering, but individuals who have lived experience of distress are often not able to utilize that experience in a meaningful way due to the stigma that surrounds madness, which is particularly pervasive amongst mental health professionals (Harris et al., 2016).

This project contributes to existing Mad Studies scholarship in several ways. First, this project applied ethical principles in research such as refusing to reproduce pain narratives (Tuck & Yang, 2014) and conversely by telling the entire story when an example is used, not merely picking and choosing relevant pieces from individual stories as the Academy often does (Costa et al., 2012). As well, this project worked to outline the fundamental assumptions as well as the philosophy of The Icarus Project in relation to psychiatry. Finally, this project began to explore the complexity of lived experience as it relates to expertise in relation to madness and distress. Continuing to articulate the complexity of lived experience works to challenge dominant

discursive frameworks that suggest mad people are not able to make rationale choices or possess legitimate expertise.

From the inception of the organization, members of the Icarus Project have asked, “what does it mean to be crazy in a world gone mad?” (The Icarus Project: “History”, n.d.). The publications created by The Icarus Project use language that challenges dominant paradigms about what it means to be “mentally ill” and to experience emotional distress and suffering. The words that we use to describe madness matters. Therefore, The Icarus Project uses vast, detailed, and mostly non-diagnostic language to explain and describe experiences of madness or distress which in turn creates more space for normal human emotion and experience. The documents produced by The Icarus Project demonstrate the organizations effort to create space for people who accept psychiatric paradigms and those who do not. The documents reviewed for this project also demonstrate the commitment of the members of The Icarus Project’s work to create new and better healing spaces by distributing knowledge generated by people who have experience with madness themselves. The Icarus Project demonstrates that biomedical models of mental distress are not the only available discourse and that we can think about distress, and in turn healing, differently.

References

- Adame, A. L. (2014). "There needs to be a place in society for madness": The psychiatric survivor movement and new directions in mental health care. *Journal of Humanistic Psychology*, 54(4), 456–475. <https://doi.org/10.1177/0022167813510207>
- Ahmed, S. (2017). *Living a feminist life*. Durham: Duke University Press.
- Ambrosini, D. L., & Crocker, A. G. (2007). Psychiatric advance directives and the right to refuse treatment in Canada. *Canadian Journal of Psychiatry*, 52(6), 397–402. <https://doi.org/10.1177/070674370705200610>
- American Sociological Association. (n.d.). Culture. Retrieved July 16, 2018, from: <http://www.asanet.org/topics/culture>
- Bell, R. (2018). Falling through the cracks: Desperate Alberta man's video shows gaps in mental health care. *CBC*. Retrieved from <https://www.cbc.ca/news/canada/edmonton/hans-mccarthy-alberta-mental-health-1.4726447>
- Bird, C. E., & Rieker, P. P. (2008). *Gender and health: The effects of constrained choices and social policies*. Cambridge: Cambridge University Press.
- Boardman, F. K. (2017). Experience as knowledge: Disability, distillation and (reprogenetic) decision-making. *Social Science and Medicine*, 191, 186–193. <https://doi.org/10.1016/j.socscimed.2017.09.013>
- Bonisteel, M., & Green, L. (2005). Implications of the shrinking space for feminist anti-violence advocacy. Presented at the 2005 Canadian Social Welfare Policy Conference, *Forging Social Futures* (pp. 1-57).
- Bracken, P. (1995). Beyond liberation: Michel Foucault and the notion of a critical psychiatry. *Philosophy, Psychiatry, & Psychology*, 2(1), 1–13. <https://doi.org/10.1353/ppp.0.0113>
- Bracken, P., & Thomas, P. (2010). From Szasz to Foucault: On the Role of Critical Psychiatry. *Philosophy, Psychiatry & Psychology*, 17(3), 219–228. <https://doi.org/10.1353/ppp.2010.0007>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in*

Psychology, 3(2), 77-101. doi: 10.1191/1478088706qp063oa

Brown, N., & Leigh, J. (2018). Ableism in academia: where are the disabled and ill academics?

Disability and Society, 33(6), 1–5. <https://doi.org/10.1080/09687599.2018.1455627>

Burstow, B. (2013). A rose by any other name: Naming and the battle against psychiatry. In *Mad Matters: A Critical Reader in Canadian Mad Studies* (pp. 79-90). Toronto, ON: Canadian Scholars' Press.

Cacioppo, S., Capitanio, J. P., & Cacioppo, J. T. (2014). Toward a neurology of loneliness.

Psychological Bulletin, 140(6), 1464–1504. <https://doi.org/10.1037/a0037618>

Canadian Mental Health Association (CMHA) Ontario. (n.d.). Are you in crisis? Retrieved July

8, 2018, from <https://ontario.cmha.ca/documents/are-you-in-crisis/>

Chamberlin, J. (1995). Rehabilitating ourselves: The psychiatric survivor

movement. *International Journal of Mental Health*, 24(1), 39-46. Retrieved from

<http://www.jstor.org.libproxy.wlu.ca/stable/41344711>

Chambon, A., Irving, A., & Epstein, L. (1999). Reading Foucault for Social Work. *Service*

Social, 50(1), 83-97. doi: 10.7202/008197ar

College of Nurses of Ontario. (2017). Practice Guideline: Consent. Retrieved from

http://www.cno.org/globalassets/docs/policy/41020_consent.pdf

Conrad, P. (1994). Wellness as virtue: Morality and the pursuit of health. *Culture, Medicine and*

Psychiatry, 18(3), 385–401.

Costa, L., Voronka, J., Landry, D., Reid, J., McFarlane, B., Reville, D., & Church, K. (2012).

Recovering our stories: A small act of resistance. *Studies in Social Justice*, 6 (1), 85-101.

ISSN: 1911-4788

Deacon, B. J. (2013). The biomedical model of mental disorder: A critical analysis of its validity,

utility, and effects on psychotherapy research. *Clinical Psychology Review*, 33(7), 846–861.

<https://doi.org/10.1016/j.cpr.2012.09.007>

Defehr, J. N. (2016). Inventing mental health first aid: The problem of psychocentrism. *Studies*

in Social Justice, 10(1), 1-18. doi:10.26522/ssj.v10i1.1326

- DuBrul, S. (n.d.). Maps to the other side: About Sascha. Retrieved July 16, 2018, from <http://www.mapstotheotherside.net/author/>
- DuBrul, S. A. (2014). The Icarus Project: A counter narrative for psychic diversity. *Journal of Medical Humanities*, 35(3), 257–271. <https://doi.org/10.1007/s10912-014-9293-5>
- Fairclough, N. (2008). A dialectical-relation approach to critical discourse analysis in social research (R. Wodak & M. Meyer, Eds.). In *Methods in Critical Discourse Analysis* (2nd ed.). Sage.
- Faulkner, A. (2017). Survivor research and Mad Studies: The role and value of experiential knowledge in mental health research. *Disability and Society*, 32(4), 500–520. <https://doi.org/10.1080/09687599.2017.1302320>
- Fletcher, E. H. (2017). Uncivilizing “Mental Illness”: Contextualizing Diverse Mental States and Posthuman Emotional Ecologies within The Icarus Project. *Journal of Medical Humanities*, 39(1), 29–43. <https://doi.org/10.1007/s10912-017-9476-y>
- Fox, N. (1997). Is there life after Foucault? Texts, frames, and differends. In *Foucault: Health and medicine*. Petersen, A., & Bunton, R. (Eds.). New York, NY: Routledge.
- Foucault, M. (1965). *Madness and civilization: A history of insanity in the age of reason*. London: Social Science Paperback.
- Foucault, M. (2006). *Psychiatric power: Lectures at the Collège de France, 1973-74*(J. Lagrange, F. Ewald, A. Fontana, & A. J. Davidson, Eds.; G. Burchell, Trans.). Basingstoke: Palgrave Macmillan. (Original lecture given 1973-74).
- Freedom Center. (n.d.). Welcome. Retrieved from: <http://www.freedom-center.org/welcome>
- Gillis, W. (2018). Court of Appeal upholds conviction for Toronto cop who shot Sammy Yatim. *Toronto Star*. Retrieved from <https://www.thestar.com/news/gta/2018/04/30/court-of-appeal-upholds-conviction-for-toronto-cop-who-shot-sammy-yatim.html>

- Gomory, T., Cohen, D., & Kirk, S. A. (2013). Madness or Mental Illness? Revisiting Historians of Psychiatry. *Current Psychology*, 32(2), 119–135. <https://doi.org/10.1007/s12144-013-9168-3>
- Grace, E. (2013). Cognitively Accessible Language (Why We Should Care). Retrieved July 30, 2018, from <http://www.thefeministwire.com/2013/11/cognitively-accessible-language-why-we-should-care/>
- Hall, W. (2012). Harm reduction guide to coming off psychiatric drugs. *Freedom Center & The Icarus Project*. Retrieved April 1, 2018, from <http://www.willhall.net/files/ComingOffPsychDrugsHarmReductGuide2Edonline.pdf>
- Harris, J. I., Leskela, J., & Hoffman-Konn, L. (2016). Provider lived experience and stigma. *American Journal of Orthopsychiatry*, 86(6), 604–609. <https://doi.org/10.1037/ort0000179>
- Health Quality Ontario. (2016). *Income and Health: Opportunities to achieve health equity in Ontario*(Rep.). Toronto: Queen's Printer for Ontario. Retrieved from: <http://www.hqontario.ca/Portals/0/documents/system-performance/health-equity-report-en.pdf>
- Hill Collins, P., & Bilge, S. (2016). *Intersectionality*. Malden, MA: Polity Press.
- Jones, M., & Pietilä, I. (2018). Expertise, advocacy and activism: A qualitative study on the activities of prostate cancer peer support workers. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 136345931878571. <https://doi.org/10.1177/1363459318785711>
- Kendall, G., & Wickham, G. (1999). *Using Foucault's Methods*. London: SAGE Publications.
- Knaak, S., Mantler, E., & Szeto, A. (2017). Mental illness-related stigma in healthcare: Barriers to access and care and evidence-based solutions. *Healthcare Management Forum*, 30(2), 111–116. <https://doi.org/10.1177/0840470416679413>
- Krücke, M. (2007). Advance directives- A step towards self-help. In P. Stastny & P. Lehmann (Eds.), *Alternatives Beyond Psychiatry*(pp. 97-104). Berlin: Peter Lehmann Publishing.

- Landry, D. (2017). Survivor research in Canada: 'Talking' recovery, resisting psychiatry, and reclaiming madness. *Disability and Society*, 32(9), 1437–1457.
<https://doi.org/10.1080/09687599.2017.1322499>
- Leblanc, S., & Kinsella, E. A. (2016). Toward epistemic justice: A critically reflexive examination of "sanism" and implications for knowledge generation. *Studies in Social Justice*, 10(1), 59–78.
- LeFrancois, B., Menzies, R., Reaume, G. (2013). Introduction. In *Mad Matters: A Critical Reader in Canadian Mad Studies* (pp. 1-22). Toronto, ON: Canadian Scholars' Press.
- Lewis, A. J. (2016). "We Are Certain of Our Own Insanity": Antipsychiatry and the Gay Liberation Movement, 1968–1980. *Journal of the History of Sexuality*, 25(1), 83–113.
<https://doi.org/10.7560/JHS25104>
- Lupton, D. (2004). *Medicine as culture: Illness, disease and the body* (2nd ed.). Los Angeles: London: SAGE Publications.
- Marriner, S. (2012). Questioning "expert" knowledges. In E. Sheehy (Ed.), *Sexual assault in Canada: Law, legal practice and women's activism*(pp. 409-450). University of Ottawa Press. Retrieved from: <https://doi.org/10.1017/cls.2014.18>
- Martin, E. (2010). Self-making and the brain. *Subjectivity*, 3(4), 366–381. Retrieved from: <https://doi.org/10.1057/sub.2010.23>
- Maynard, R. (2017). *Policing Black lives: State violence in Canada from slavery to the present*. Winnipeg, MB: Fernwood.
- Miller, L. (2000). The poverty of truth seeking: Postmodernism, discourse analysis, and critical feminism. *Theory and Psychology*, 10(3), 313–352.
- Mitchell-Brody, M. (2014). The Icarus Project: Dangerous Gifts, iridescent visions, and mad community. In *Alternatives Beyond Psychiatry* (Kindle ed., pp. 2343-2491). Berlin: Peter Lehmann Publishing.
- Meerai, S., Abdillahi, I., & Poole, J. (2016). An Introduction to Anti-Black Sanism. *Intersectionalities*, 5(December 2016), 18–34.

- Morrow, M. (2007). Critiquing the "psychiatric paradigm" revisited: Reflections on feminist interventions in mental health. *Resources for Feminist Research/Documentation Sur La Recherche Feministe*, 32(1-2), 69-85. Retrieved from <https://libproxy.wlu.ca/login?url=https://search-proquest-com.libproxy.wlu.ca/docview/61655342?accountid=15090>
- Morrow, M. (2017). "Women and Madness" revisited: The promise of intersectional and mad studies frameworks. In *Critical Inquiries for Social Justice in Mental Health* (pp. 33-59). Toronto, ON: University of Toronto Press.
- National Collaborating Centre for Aboriginal Health (NCCAH). (2013). An overview of Aboriginal health in Canada. Retrieved from <https://www.cnsa-nccah.ca/docs/context/FS-OverviewAboriginalHealth-EN.pdf>
- Parker, I. (2015) *Critical discursive psychology*, Palgrave Macmillan Limited. ProQuest Ebook Central. Retrieved from: <https://ebookcentral-proquest-com.libproxy.wlu.ca/lib/oculwlu-ebooks/detail.action?docID=2057854>
- Paterson, K., & Hughes, B. (1999). Disability Studies and Phenomenology: The carnal politics of everyday life. *Disability and Society*, 14(5), 597–610. <https://doi.org/10.1080/09687599925966>
- Petersen, A., & Bunton, R. (Eds.). (1997). *Foucault: Health and medicine*. New York, NY: Routledge.
- Pies, R., Thommi, S., & Ghaemi, N. (2011, July). Getting it from both sides: foundational and antifoundational critiques of psychiatry. *Psychiatric Times*, 28(7), 1. Retrieved from <http://link.galegroup.com.libproxy.wlu.ca/apps/doc/A264271222/AONE?u=wate18005&sid=AONE&xid=6db88bec>
- Poole, J. M., Jivraj, T., Arslanian, A., Bellows, K., Chiasson, S., Hakimy, H., Pasini, J., Reid, J. (2012). Sanism, 'mental health', and social work/education: A review and call to action. *Intersectionalities: A Global Journal of Social Work Analysis, Research, Polity, and Practice*, 1(1), 20–36. <https://doi.org/1925-1270>
- Rabinow, P., & Rose, N. (Eds.). (2003). *The essential Foucault: Selections from the essential works of Foucault 1954-1984*. New York: New Press.

- Rentmeester, C. A. (2012). Postcolonial bioethics -- a lens for considering the historical roots of racial and ethnic inequalities in mental health. *Cambridge Quarterly of Healthcare Ethics : CQ: The International Journal of Healthcare Ethics Committees*, 21(3), 366–374. <https://doi.org/10.1017/S0963180112000084>
- Rose, N. S. (1985). *The Psychological Complex: Psychology, politics, and society in England, 1869-1939*. London: Routledge & Kegan Paul.
- Russo, J., & Beresford, P. (2015). Between exclusion and colonisation: seeking a place for mad people's knowledge in academia. *Disability and Society*, 30(1), 153–157. <https://doi.org/10.1080/09687599.2014.957925>
- Saldaña, J. (2013). *The coding manual for qualitative researchers* (2nd ed.). Los Angeles, CA: SAGE.
- Sealy, P., & Whitehead, P. C. (2004). Forty Years of Deinstitutionalization of Psychiatric Services in Canada: An Empirical Assessment. *Canadian Journal of Psychiatry*, 49(4), 249–257. <https://doi.org/10.1177/070674370404900405>
- Sealy, P. A. (2012). The impact of the process of deinstitutionalization of mental health services in Canada: An increase in accessing of health professionals for mental health concerns. *Social Work in Public Health*, 27(3), 229–237. <https://doi.org/10.1080/19371911003748786>
- Spade, D. (2015). *Normal life: Administrative violence, critical trans politics, and the limits of law*. Durham: Duke University Press.
- Starkman, M. (2013). The Movement. In *Mad Matters: A Critical Reader in Canadian Mad Studies* (pp. 27-37). Toronto, ON: Canadian Scholars' Press. (Original work published 1981)
- Tam, L. (2013). Whither Indigenizing the mad movement? Theorizing the social relations of race and madness through conviviality. In B. LeFrancois, R. Menzies, & G. Reaume (Eds.), *Mad matters: A critical reader in Canadian Mad Studies*(pp. 281-297). Toronto, ON: Canadian Scholars' Press.

- The Icarus Project. (n.d.). What We Do. Retrieved April 11, 2018, from <https://theicarusproject.net/what-we-do/>
- The Icarus Project. (n.d.). Mission, Vision, & Principles. Retrieved April 11, 2018, from <https://theicarusproject.net/mission-vision-principles/>
- The Icarus Project. (n.d.). Handouts. *Navigating crisis*. Retrieved April 11, 2018, from <https://theicarusproject.net/resources/publications/handouts/>
- The Icarus Project. (n.d.). History. Retrieved April 11, 2018, from <https://theicarusproject.net/welcome-to-the-icarus-project/origins-and-purpose/>
- The Icarus Project. (2015). Madness & Oppression: Paths to Personal Transformation & Collective Liberation. Retrieved from <https://www.pdf-archive.com/2015/11/06/madnessandoppressionguide/madnessandoppressionguide.pdf>
- Tietze, T. (2015). Peter Sedgwick: Mental health as radical politics. *Critical and Radical Social Work*, 3(1), 103-117. <http://dx.doi.org/10.1332/204986015X14234701186107>
- Tuck, E., & Yang, W. (2014) "R-Words: Refusing Research." in *Humanizing Research: Decolonizing Qualitative Inquiry with Youth and Communities*. D. Paris and M.T. Winns. (Eds.) Thousand Oaks: SAGE Publications. Print. 223-247.
- Voronka, J. (2015). *Troubling inclusion: The politics of peer work and 'people with lived experience' in mental health interventions* (Order No. 10017839). Available from ProQuest Dissertations & Theses A&I; ProQuest Dissertations & Theses Global. (1767789279). Retrieved from <https://libproxy.wlu.ca/login?url=https://search-proquest-com.libproxy.wlu.ca/docview/1767789279?accountid=15090>
- Willig, C. (2008). *Introducing qualitative research in psychology*. Maidenhead, England: McGraw Hill/Open University Press.
- Ziegler, L. (2007). Upholding psychiatric advance directives: "The rights of a flea". In P. Stastny & P. Lehmann (Eds.), *Alternatives Beyond Psychiatry*(pp. 97-104). Berlin: Peter Lehmann Publishing.

Appendix A

Selection of Language used by The Icarus Project to Describe Diverse Human Experiences.

Madness

People who experience the world in ways that are often diagnosed as mental illness

Different states of being

Human Behaviour

Emotional Distress

Sensitivities

Mental health

Different ways of being in the world

Experiences of trauma and/or violence

Lived experience

Suffering

Emotional crisis

Extreme emotional states

Experiences labelled “mental disorders”

Extreme emotional distress

Wild mood swings

Unusual beliefs

Disruptive behaviour

Mysterious states of madness

Overwhelming suffering

Emotional Extremes

Mental Suffering

Diverse-ability (as opposed to disability)

Emotionally wounded

Sensitive

Unusual people

Difference

Extreme states of consciousness

Altered states of consciousness

Impact of oppression

Difficult emotions

Gifts

Talents

Nonconformist beliefs

Mental difference

Brilliance