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Occupation, Identity and Belonging within Community: Experiences of Mental Health Disability

Thesis presented by

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for the degree of

Master of Science (MSc) by Research in Occupational Therapy

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Declaration

"This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism."

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For, Jane, Dave and Tim I am entirely in awe of your courage and generosity.

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Abstract

Background

This is a qualitative research study exploring the perspectives of Irish people with self-reported mental health disability in participating in occupation within their community environments. The relatedness of occupation to health and the concept of belonging requires further research and understanding within the discipline of Occupational Science and within the practice of Occupational Therapy.

Methodology

Purposive sampling was employed to recruit three participants, from one national mental health support organisation. A phenomenological and narrative framework was adopted in this research. This informed the use of narrative interviews and observation methods to gather data about occupations enacted by participants within their community environments. Open ended narrative interviews were adopted to encourage storied accounts of participants' experiences, with each participant engaging in two interviews. Following the first interview, each participant collaborated with the researcher in planning an observation session, with the researcher as complete participant, in a chosen occupation within their local, familiar environment. Following this each participant engaged in a second interview with the researcher.

Data Collection and Analysis

Digital audio recordings were transcribed anonymously and verbatim from interviews, coupled with field notes from observations, using thematic analysis. This analysis upheld the integrity of each story while illuminating shared meaning of participants' chosen occupations.

Findings

In answer to the research questions, two primary themes were identified, with each theme encompassing two subthemes. The first theme "Experiencing Normality and

Promoting Health" explores how participants in this study experienced feeling or anticipated feeling normal through their participation in occupation. Additionally, they chose occupations to promote their physical and mental health when navigating changes to their identities as a result of their mental health distress or disability. The second theme was "Meaning Making and Experiences of Inclusion and Exclusion within Community" exploring participants meaning making through occupation in their local environments, within places and amongst others. The first subtheme captures how participants participated in meaning making with others. The second focuses on their experiences of inclusion and exclusion with stigma emerging from their surrounding environments, impacting feelings of belonging.

Discussion

The findings of this study inform understanding of occupation and expand knowledge of its relationship to health, specifically mental health. It contributes to existing research concerning the impact of the social world on a person's occupational choices, possibilities and resultant identities. Further these findings have elicited greater understanding about the meaning of these occupations to participants and how this enabled their participation through "being" and "belonging" in their communities.

Conclusion

The results of this study contribute to theory generation of occupation within the discipline of occupational science and to the clinical practice of occupational therapy. The findings of the current research indicate that stigma and experiences of exclusion prevail for people with mental health disabilities. Results also find that participation in occupation, within affirming environments can create experiences of normality and promote health. Further, participation in occupation fosters experiences of inclusion and belonging.

Glossary of Terms

The following provides a summary of symbols and their associated meanings used within participants' interview excerpts within this study:

- Underlined text: Conveys emphasis in speech.
- … ellipses (three full-stops): Indicates where a quote had been edited for relevancy, for example removing repeated words. In this instance it may appear at the start, middle or end of a quote.
- (pause): Indicates that a participant pauses mid conversation to consider.

The following terms appear in participants' narratives and are explained as:

- Peer led group: a group created and facilitated by people with mental health disabilities for people with mental health disabilities.
- Mental Health support group: local mental health support group offering weekly, structured meetings facilitated by peers.
- Mental Health support organisation: National mental health support organisation with local network of support groups.
- Community based group: A public group facilitated in the community.
- Mental Health community: A drop in peer community, run by peer members with formal supports, offering various day time and weekend services including paid work preparation.
- Mental health disability: denotes a person who has a mental health diagnosis and uses formal or peer led mental health services and experiences barriers to engagement in activity (i.e. Occupation) due to factors such as societal or attitudinal issues.

Abbreviations

- Occupational Science (OS)
- Occupational Therapy (OT)
- The International Classification of Functioning (ICF)
- The World Health Organisation (WHO)
- The United Nations (UN)
- The United Nations Convention of the Rights of People with Disabilities (UNCRPD)
- A Vision for Change (AVFC)
- Mental Health Reform (MHR)
- The Health Service Executive (HSE)
- The World Federation of Occupational Therapists (WFOT)
- The National Disability Authority (NDA)
- The European Network of (ex) – Users and Survivors of Psychiatry (ENUSP)
- The American Association of Occupational Therapists (AOTA)
- The Model of Human Occupation (MOHO)
- The Person Environment Occupation (PEO) Model
- The Canadian Model of Occupational Performance (CMOP)
- The Capabilities Approach (CA)
- The Disability Creation Process Model (DCP)
- Occupational Justice (OJ)
- The Independent Living Movement (ILM)
- The National Disability Strategy Implementation Group (NDSIG)

Chapter 1: Introduction

1.1 Study Background

In 1980, Elizabeth Yerxa, the Occupational Science (OS) pioneer, evocatively described the transforming health landscape propelled by considerable social change, pervading the clinical profession of Occupational Therapy (OT). Yerxa (1980) considers, amongst other issues, western societal overreliance on *"technique and objectivism",* detached from environmental connection. Additionally, she considers how a pathological interpretation of disability applies a perspective of chronicity to those who are disabled, solidifying their sick roles. For example, she contends that treatment of the mentally ill *"constitutes an ethical and social disgrace"* (p. 531), anticipating sustained restriction of resources to this group. Confronting this situation, she corrals OT to *"preserve and enhance a climate of caring"*. Entailing sharing the OT view of health through illustrations of a person's capability, collaborating with patients and redressing discrimination toward those with disabilities (Yerxa, 1980). She asserts that a view of disabled people may alter:

> *"… of 'chronically ill people in need of tolerance', to that of persons who can achieve healthfulness through participation in purposeful activity"* (Yerxa, 1980, p. 534).

Later, Yerxa (1994), describes the increased potency of the *disabled population*[1], who were both under and misrepresented in policy development, triggering widespread shifts toward an inclusive health agenda. She coined this era *"Millennium of Occupation"* nominating OS as the discipline prepared to redress this inequity, through a celebration of personal autonomy and capabilities (Yerxa, 1994). Prior, the Ottawa Charter published in 1984 (WHO, 2019), espoused *"enabling, advocating and*

[1] I have consciously used this term as per my rationale outlined in section 1.2.1

mediating" as the primary mechanisms to protect and promote health for all (Townsend & Wilcock, 2004, p.78). This charter detailed the role of the environment, including society in health promotion, calling for health promotion to span governmental and societal sectors, realised through collaborative policies (Townsend & Wilcock, 2004). Following this, in 2001 the World Health Organisation's (WHO) International Classification of Functioning (ICF) was introduced, a global health framework addressing participation and attempting to contextualise disability (Hemmingsson & Jonsson, 2005; Law, 2002; WHO, 2001). Further, the publication of the United Nations (UN) Convention of the Rights of People with Disabilities (UNCRPD) (UN, 2006) became the first document to explicate the rights of disabled people (Harpur, 2012). Russo and Wolley (2020) reflect on the impact of the social model of disability in advancing the rights of those with physical and sensory disabilities through use of *"collective first-person knowledge*" (p.158). Considering, people with psychiatric diagnoses or psychosocial disabilities, they espouse the need for a theoretical model effective enough to implement the UNCRPD (Russo & Wolley 2020).

Prior to the UNCRPD, the concept of recovery emerged from the consumer movement within mental health, embracing humanity, rights, and hope in the personal process of recovery (Rebeiro Gruhl, 2005). Many international health administrations have adopted this lens to drive change in mental health policy and services (Health Service Executive, 2018; Lal, 2010; Lloyd et al., 2008). However, it is challenged by survivors and service users alike as being subsumed into existing mental health services diminishing its progressiveness (Russo & Wolley 2020) and overemphasising personal responsibility (Edwards & Thomas 2018). O'Reilly and Boland (2012) considered the shifts occurring within Irish mental health policy. Restoration of lost rights for residents of mental health institutions, through years of deprivation and marginalisation, were addressed through the 1984 policy, Planning for the Future (O'Reilly & Boland, 2012). This policy aimed to establish community services making mental health more visible and mainstreamed. Although admissions reduced, the formation of community mental health multidisciplinary teams was incomplete and overall community services underdeveloped (O'Reilly & Boland, 2012). Alongside the launch of the UNCRPRD in 2006, the Irish Government published

"A Vison for Change: Report of the Expert Group on Mental Health Policy (AVFC). It attempted to refocus Irish mental health service provision to communities driven by a person-centred vision (Government of Ireland, 2006). Within this policy, mental health is understood as:

> *"…. broader than an absence of mental disorders; that poor mental health affects our ability to cope with and manage our lives, particularly during personal change and through key life events, and decreases our ability to participate fully in life; and that mental health is an essential component of general health, which it underpins"* (Government of Ireland, 2006, p.16).

Mental health problems are described as having high population prevalence, with the WHO (2003) cited, in ranking mental health disorders second in terms of global disease burden (Government of Ireland, 2006). One of the many recommendations of AVFC was:

> "…. *all citizens should be treated equally. Access to employment, housing and education for individuals with mental health problems should be on the same basis as every other citizen"* (Government of Ireland, 2006, p.35).

This language clearly intends to restore the rights of people with mental health problems to equal footing with all Irish citizens. Connectivity with others, advocacy, peer support, employment and education are prioritised. Additionally, AVFC's fourth chapter discusses belonging and participation, promoting social inclusion strategies to reduce the impact of the *"cycle of exclusion"* (p.34) experienced by people with mental health problems (Government of Ireland, 2006). Nonetheless, Mental Health Reform (MHR) in their report: A Vision for Change Nine Years On: A coalition analysis of progress (MHR, 2015) found several inadequacies including: inconsistent access to employment and housing, discriminative attitudes triumphant, and social inclusion yet unrealised (MHR, 2015). Its limited progress is also evidenced by the lack of

staffing resources to fully implement this policy. Occupational therapists were identified as essential to the multidisciplinary team however, O'Reilly and Boland's 2010 survey revealed only 190 out of 561 were employed in Irish community mental health services (O'Reilly & Boland, 2012). Three years after this survey, despite an increased number of mental health multidisciplinary teams, staffing remained insufficient (MHR 2015). The significance bestowed to the participation of people with mental health problems within AVFC is evident, while the lack of OT development to implement its aims is still felt. This compelled me to undertake research within an Irish context, fortifying the OT role in enabling participation. My rationale is presented below.

1.2 Research Rationale

In the following section, I will define mental health disability, outline my rationale for pursuing this research and detail my personal standpoint.

1.2.1 Defining Disability and Mental Health Disability within this Study

Russo and Shulkes' (2015) discourse about the use of diverse terms applied to those who have experienced psychiatric treatment, situated within their membership of the European Network of (ex) – Users and Survivors of Psychiatry (ENUSP), was stimulating given my own work as a service provider. Two primary terms are discussed: distress or disability, with disability holding evocative personal, cultural and economic meaning, often resulting in a complex relationship for users and survivors (Russo & Shulkes, 2015). The authors conclude that the right to self-determine one's identity is essential and that the safety to explore this is essential in upholding and progressing the rights of users and survivors. Russo and Shulkes' dialogue underpins the adoption of the term self-determined mental health disability within this research. Although from a differing perspective than that of mental health, Salmon (2013) explored young disabled peoples' experience of stigma in forming friendships and reflected on her deliberate adoption of the term disability.

She reasoned that this term illustrates the societal oppression toward those appearing different to established norms. For this reason, too, the term disability was used in this research. The term mental health disability [2]is employed to account for the interplay between personal and environmental factors, including societal attitudes, policy and political perspectives, in creating disability, when people experiencing mental health distress or with a mental health diagnosis, attempt to participate in valued occupation.

I will attempt to explore disability perspectives further in this thesis, but first I will define disability within the context of the current research. The Irish Disability Act (2005) defines disability as:

> *"…a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment"* (Government of Ireland, 2005, p.6).

In the 2016 Irish census the population was recorded as 4,757,976, with 123, 515 people registered as having a psychological or emotional condition, however, presence of multiple disabilities impacts accuracy (National Disability Authority, 2016). In the National Disability Authority's (NDA) 2017 survey of the Public Attitudes to Disability, *"mental health difficulty"* was found to be the second most recognised term when identifying conditions associated with the term *"people with disabilities"*

[2] The term disability was carefully chosen to denote a person who has a mental health diagnosis and uses formal or peer led mental health services and experiences barriers to engagement in activity (i.e. Occupation) due to factors such as societal or attitudinal issues. In AVFC's note on terminology (2006) they describe: *"The term mental health problem has been used throughout this document to describe the full range of mental health difficulties that might be encountered, from the psychological distress experienced by many people, to serious mental disorders and illnesses that affect a smaller population."* (Government of Ireland, 2006, p.6). I felt using terms like mental health problems or mental health difficulties excluded the significance of the environment and could preclude the variety of perspectives existing and evolving within the realm of mental health. For example, the participants in the current study chose different terms such as *"serious mental illness"* and *"psychiatric".* Further, in my stance as a service provider, while attending to consumer and ex-user forums, I hoped to provide an authentic position from which to comment as I personally do not have self-knowledge of living with a mental health diagnosis or using mental health services. It was beyond the scope of this thesis to consider all mental health perspectives expansively. I have deliberately reviewed research from a variety of disability perspectives, including that from mental health, to consider and elucidate key theoretical concepts relevant to my research questions.

(NDA, 2017). Mental health is also encapsulated by the UN under the rubric of disability, as detailed below:

> *"The term persons with disabilities is used to apply to all persons with disabilities including those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various attitudinal and environmental barriers, hinders their full and effective participation in society on an equal basis with others"* (UN, 2019).

The definition offered within the Irish Disability Act (2005) does not appear to account for the environmental creation of disability, thus, the UN's (2019) definition is adopted in this study.

1.2.2 Detailing my Rationale for Pursuing this Research

Occupation and participation are foregrounded within AVFC, but operationally, progress would appear limited. Considering this, perhaps it is due to the shortage of occupational therapists, who, in their absence, are unable to advocate for the needs of those with disabilities, a key strategy highlighted by Yerxa (1980) in preserving a *"climate of caring"*. Or maybe it is attributable to the sustained dominance of the medical model within mental health services (Ashby, Ryan & James, 2015). Wilcock (1999) offered me some clarity, detailing occupation's role in health, consistent with the profession's founding beliefs and detaching it from damaging ideals pressed by more dominant health and political perspectives. She considers the impact of the medical model on the development of OT, with adopted medicalised terminology, describing states of health or impairment, compromising our unique focus (Wilcock, 1999). Occupational therapy continues to grapple with the medical model, affecting our realisation of client centredness and consistency with ideology capturing the environmental construction of disability (Ashby et al., 2015; Gupta, 2016; Wilcock, 1999). Through the contributions of my research, I believe that greater

understanding of occupation and consistency in the way this is discussed will disentangle OT from medicalised reasoning.

Embarking on this research project, I wanted to learn more about belonging and inclusion espoused within the AVFC and reiterated in Ireland's A National Framework for Recovery in Mental Health (HSE, 2018). Through this framework, occupation (although not through this term) is centrally placed, within the five themes fostering recovery: Connectedness, Hope, Identity, Meaningful Role and Empowerment (HSE, 2018). Within OS, *"belonging"* a dimension of occupation, was adopted to explain the experience of interacting with and relating to others (Chisman & Brooks, 2018; Hammel, 2004; Rebeiro, Day, Semeniuk, O'Brien & Wilson, 2001). However, the possibility of belonging through occupation can be withheld as well as promoted by society (Hocking, 2017). Key to belonging, is access to others with shared experience (Rebeiro, 2001). Exclusion stemming from stigma and marginalisation invalidate citizenship (Hamer et al., 2017; Hamer et al., 2014) diminishing occupational possibilities or the forms of doing endorsed by others, (Laliberte Rudman 2002) and belonging (Rebeiro et al., 2001). My research raises awareness of the experience of belonging for Irish people with mental health disability as they enact occupation while navigating their community environments.

Stigma and social exclusion experienced by those using mental health services persists (Fieldhouse, 2012; Lipskaya-Velikovsky et al., 2016; NDA, 2017; Rebeiro et al., 2001). Further Salmon (2013) called for authentic inclusion, extending beyond that of just sharing spaces, confronting stigma directly. Stigma reduction within Ireland has been actualised through the Green Ribbon Campaign which has partnered with community and social organisations in using advertising, social media and awareness events to promote increased discussion about mental health (See Change, 2017). This campaign recognises the importance of mobilising the social environment to increase acceptance and openness helping to reduce stigma as a roadblock to realising the right to mental health. Positive impact has been captured including 3 of 4 people discussing mental health and increased presence on social media when compared to the 2016 campaign (See Change, 2017). However, stigma reduction is likely to have little impact without inclusion. It is more promising to see clear attempts within the National Disability Inclusion Strategy 2017 -2021

(Department of Justice, 2017) to increase access and participation in work and education for people with disabilities. With this strategy citing throughout the importance of "*reaching"* or *"maximising potential"* through meaningful and beneficial opportunities. I believe OT is pivotal to realising this potential, in the identification of environmental barriers to occupation. Further, enabling participation through meaningful occupations such as education, offers disabled people an identity outside of that as "*chronically ill people in need of tolerance"* (Yerxa, 1980, p. 534). It is clear from the above campaign and strategy that greater progress toward true inclusion is warranted for disabled people.

1.2.3 Author's Standpoint: Views, values and attitudes

In planning this research, I considered the influences on my own clinical practice. I considered how these influences shaped my reasoning with the people with whom I work in my capacity as a Mental Health Occupational Therapist within the Irish Health Service Executive (HSE). During this research project, I assumed a managerial role, gaining greater insights into the degree of proximity of everyday clinical practice to fundamental theoretical tenets within OS and OT. The World Federation of Occupational Therapists (WFOT) in their position statement: Occupational Therapy and Mental Health (2019) describe how:

> *"Occupational therapists enable the participation and engagement of people in everyday living by using a holistic, bio-psychosocial, person-centred approach that encourages individuals to use their existing capabilities and strengths"* (WFOT, 2019, p.1).

Heeding Yerxa's (2000) advice to make one's assumptions *"explicit",* I believe my role as an occupational therapist is to enable participation in meaningful occupation, promoting health. However, my clinical interventions have often been challenged by competing discourses, inconsistent OT terminology and contrived clinical environments. Further, within my experience of working in Irish mental health

services, I don't believe that all occupation is health promoting, but that the right to choose occupation is paramount. I found myself repeatedly reflecting on whether the interventions I was offering were truly client centred, sufficiently situated in occupation and indeed enabling participation. It was my intention to study how occupation is used in natural, community contexts to further understand a person's participation, adding to the academic understanding and clinical application of occupation.

1.3 Finalising my Research Questions

Through my research questions I sought greater understanding of the experiences of people with mental health disability as they participated in occupation within their communities. Within these questions, occupation and participation are foregrounded. Reflection over time resolved in the below configuration (Figure 1). The rationale and literature review underpinning these questions will be detailed in the following chapter.

1.3.1 Figure 1: Final Research Questions

1. How do people with self-reported mental health disability participate in or experience occupation in their local, familiar environments?
2. Do people with self-reported mental health disability express feelings of belonging to their community and other environments through enactment of occupation?
3. How do participants feel their environment has influenced their occupational possibilities?

1.4 Considering the Importance of this Study

Albeit attention attributed to occupation within Irish mental health policy, I am concerned it may be portrayed as only health promoting, as a mechanism to become a recognisable, contributing member of society. This, I believe, makes occupation vulnerable to prescription, succumbing to a medicalised or culturally insensitive rationale, overlooking the right to choose occupation. Scholars from within OT and OS have captured the significance of occupational choices as a determinant of mental health and wellbeing (Nagle, Cook & Polatajko, 2002; Sutton, Hocking & Smythe, 2012; Townsend, 1997). Further, choice of occupation is deemed a right by OS (Wilcock & Townsend 2004; WFOT 2019). Others have drawn attention to the less understood aspects of occupation and how it relates to health (Hitch, Pépin & Stagnitti, 2014b; Stewart, Fischer, Hirji & Davis, 2016). For example, Stewart, Fischer, Hirji and Davis (2016) assert that occupations should be portrayed as neither health promoting nor reducing but *"neutral*", with either outcome dependent on the environment in which its situated. Elaborating, they determine this environment as including physical, sociocultural, historical and political features, while encompassing each person's engagement and meaning bestowed upon the occupation (Stewart et al., 2016). To summarise the founding and sustained belief of OT and OS is the relatedness of occupation to health and wellbeing (Wilcock, 1999; Yerxa, 1980, 1994) however all facets of this complex phenomenon require further research to ascertain this position (Hitch et al., 2014b; Stewart et al., 2016). Contributions from my research offers new insights into the types of occupations chosen by the participants and the importance of these choices to their health.

The voices of services users with lived mental health experience emerge in Irish mental health policy (Government of Ireland, 2006; HSE, 2018). The scale of privilege of service provider and user is somewhat recalibrated by the acknowledgement that mental health recovery journeys are uniquely subjective (HSE, 2018). However, I find traditional referrals for *"functional assessment"*[3]commonplace. For example, independence was determined by Swedish

[3] A type of occupational therapy clinical assessment to objectively establish a person's independence.

occupational therapists working in mental health and learning disability to be the optimal goal of therapy (Kjellberg, Kåhlin, Haglund & Taylor, 2012). But this idea of independence is restrictive, discounting a person's preference and ability to seek support and value relationships (Hammell, 2014) while endangering client centredness (Kjellberg et al., 2012). Coinciding with independence, referrals for sourcing employment permeate my OT practice. Attention has been drawn by OS to the significance of paid employment within western society (Blank, Harries & Reynolds, 2015; Kantartzis & Molineux, 2011; Unruh, 2004; van Niekerk, 2016). Clark (1997) discusses how this overvaluation of paid employment has led to an American culture of consumerism fuelled by trends toward overworking, creating a dissatisfying and stressful life cycle. Such norms held by societies both in work and independence may have the potential to privilege some occupations and discount others. This convinced me of the need to research how occupation is personally experienced, disseminating findings to influence how it is understood generally and in mental health policy.

Wilcock (1999) explains occupation as a *"synthesis"* of the dimensions of doing, being and becoming. "*Doing"* establishes the basic enactment of occupation to influence health, both positively and negatively, as well as contributing to society. Through *"being"* a person can be true to themselves and their nature. Both doing and being influence *"becoming"*, whereby a person is constantly changing through occupation (Wilcock, 1999). Through this research I hoped to highlight the importance of focusing on all of Wilcock's dimensions within OT in mental health. I hope to reduce attention from the visible dimension of *"doing"* while reiterating the subjective experience of occupation, as other scholars have (Hocking, 2000; Pierce, 2001). This I hope will lessen any notions of recovery as that which is only seen or deemed conventional, and that OT's client centredness is enhanced.

1.5 Thesis Overview

People with a self-determined mental health disability, encounter everyday obstacles to their participation in occupations, impacting their identities and experiences of belonging within their communities. Occupation and participation are vital components of the current conceptualisation of health and related clinical services. Further, they are significant to understanding and integrating perspectives relating to disability, mental health and human rights. In the next chapter, I review pertinent literature, delving deeper into these perspectives and discourses. Within chapter three, I outline my methodology, including the underlying research framework, methods and validation strategies adopted. Research findings are presented in chapter four, collated in two primary themes encompassing excerpts of individual and collective participant narratives. Chapter five is dedicated to the discussion of this study's findings amongst pertinent literature. Lastly, in chapter six I present my conclusions, considering implications for OS and OT alike.

Chapter Two: Literature Review

2.1 Literature Review Chapter Overview

This chapter is devoted to reviewing the works of prominent scholars, relevant to my research questions. It is divided in two parts. Firstly, I will introduce and define the concepts of occupation and participation, across health, disability and rights perspectives. In the second part, I will analyse the constructs of occupation and participation critically as they relate to one another and relevant literature in the fields of health, OS and human rights. This literature review provides a backdrop from which I will later discuss the findings of my research study.

2.2 Literature Review Part One: Introducing and Defining Occupation and Participation

Given the significance of the concepts of occupation and participation to my research and of their relatedness to one another I believe they warrant thorough examination. Part one is thus dedicated to their definition and introduction encompassing the first four sections of this chapter.

2.2.1 Occupational Science and Occupational Therapy

Defined by WFOT, OT is: "*... a client-centred health profession concerned with promoting health and well-being through occupation*" (WFOT, 2012). Occupational therapists use occupation as a therapeutic medium to improve health (Jackson, Carlson, Mandel, Zemke & Clark, 1998; Pierce, 2001; Price & Miner, 2007; Yerxa,

1998). For example, The Well Elderly Study, a randomised control trial, unequivocally demonstrated the positive effects of occupation on health through the implementation of a preventative therapeutic OT programme, grounded in OS (Clark, 1997; Jackson et al., 1998). Results found that participants identified and enacted a repertoire of health promoting occupations (Jackson et al., 1998). The authors suggest that participants navigating complex change chose meaningful occupations, embedded within their lifelong occupational stories to adapt to new circumstances (Jackson et al., 1998).

In a quest to advance the understanding of occupation, OS emerged as the academic discipline dedicated to its exploration and knowledge of humans as occupational beings (Clark et al., 1991). Clark et al. (1991) championed the birth of OS, detailing its remedies in clarifying and promoting the relationship of occupation to human health. Amongst these, was a shared vision adjoining a scholastic approach in researching the phenomenon of occupation, while employing interdisciplinary collaboration to synthesise knowledge. Although distinct from the profession of OT, Clark (2006) refers to their alliance as *"critical"* citing the continued need for shared knowledge, expanding numbers of scholars and clinicians, protecting concurrent growth. As OS and OT continue to evolve, several theoretical dialogues have emerged. The focus on a person's subjective experience has been challenged (Dickie, Cutchin & Humphry, 2006), alongside need for critical reflexivity (Phelan, 2011). While dominant discourses have infiltrated, such as the enduring presence of the medical model in healthcare (Ashby et al., 2015; Hammel, 2017; Kjellberg et al., 2012; Mattingly, 1991; Wilcock, 1999). Such discussion is deemed necessary, with varied research methods advocated to study the complexity of occupation and advance OS (Clark 2006; Laliberte Rudman et al., 2008).

2.3 Introducing and Defining Occupation

General understanding of occupation creates confusion when compared to definitions emerging from OT and OS, particularly in underestimating the complexity

of this phenomenon (Occupational Terminology Interactive Dialogue, 2001). The founding aim of the academic discipline of OS was:

> *"…. to generate knowledge about the form, the function, and the meaning of human occupation"* (Zemke & Clark 1996, Preface vii).

Establishing scholars of OS stressed the importance of researching this complex phenomenon (Yerxa, 2000), however, consensus, is not yet achieved (Carlson, Park, Kuo, & Clark, 2014; Laliberte Rudman et al., 2008). Within this section I will discuss the characteristics of occupation through review of key scholarly perspectives from OS.

2.3.1 Occupation as defined within Occupational Science

As a theoretical construct within OS and OT, occupation has been deemed complex (Wilcock, 1999) and diverse (Hocking, 2000). Occupation is regarded as necessary to life, affording it absolute prominence in understanding human behaviour and health (Carlson et al., 2014; Clark et al., 1991; Yerxa, 2000). It is determined by choice, imbued with meaning (Clark et al., 1991) and is ubiquitous (Zemke & Clarke 1996, Preface ix). In her research exploring meaningful existence in old age Jackson (1996) defines occupations as:

> *"…. Culturally and personally meaningful activities in which individuals partake on a daily basis or at various times throughout their lives"* (Jackson, 1996, p. 341).

Expanding, Jackson (1996) details five theoretical tenets of OS. First, the understanding of humans as occupational beings, in which we share an innate drive to be occupied. Secondly, people author their occupational stories, based on the choices and identities they forge throughout life. Thirdly, located within these stories, is the search for meaning, with subsequent efforts in this pursuit imbued with symbolism. At its core, this theory celebrates the adaptability of humanity in its

perpetual quest for learning to construct a healthy, meaning imbued life. Finally, occupations are situated within significant political, sociocultural and physical environments in which they may be enabled or disabled, altering these contexts as a result (Jackson, 1996).

2.3.2 Theoretical Underpinnings of Occupation within Occupational Science

Within this subsection I will explore prominent theories of occupation within OS. The Occupational Terminology series published by the Journal of Occupational Science (2001), offered a forum for academics and readers to debate new terms as well as the central construct of occupation. Within this dialogue, Rebeiro (2001) appealed for the revision of terminology to ensure its pragmatic use in OT. While Clark (2006) advocates for further attempts to fortify the discipline on the fulcrum of occupation, sustaining multidisciplinary input, adding that this pivots about our responsiveness to changing socio-political circumstances. But there is continued inconsistency regarding the emphasis and description of interdisciplinary working (Laliberte Rudman et al., 2008).

Wilcock (1999) refers to, to the *'arbitrary categories'* of occupation, diminishing occupational therapists' understanding of occupation and resultant difficulty disseminating its potency (Wilcock, 1999). This claimed theoretical ambiguity, resonates with Nelson's (1988) earlier intentions to expand understanding and limit vague terminology, by defining occupation as: "… *A relationship between occupational form and occupational performance..."* (Nelson, 1988, p. 634). With occupational form deemed the:

> *"…. pre-existing structure that elicits, guides, or structures subsequent human performance"* (Nelson, 1988, p. 633).

And the related construct of occupational performance defined as: *"… the human actions taken in response to an occupational form"* (Nelson, 1988, p. 633). Nelson expands occupational form by situating it in the sociocultural environment. Occupations are delineated through *"group consensus"* but infrequently so, creating

form variations, determined by a unique cultural press (Nelson 1988, p.634). An occupational form will impact performance but relative to the person's interpretation of the occupational form, their history, development, attributes, situated environments and meaningfulness (Nelson, 1988). Based on these transactions, occupation is deemed dynamic (Nelson, 1988), a characteristic evident in Wilcock's (1993; 1999) theoretical perspective discussed below.

Later, Wilcock (1993) describes occupation as the bedrock from which a person interacts with their society and communities, integrating social values and cultural expectations (Wilcock, 1993). It is also identified as the mode through which people demonstrate their capacity for meeting societal demands and conferring capability (Wilcock, 1993). Wilcock (1993) uses the term occupational being to describe humanity's drive for purpose, survival and advancement. Wilcock's (1993) theory aligns with Yerxa's (2000) determination of human evolution to become occupational beings, mastering basic survival and navigating an increasingly complex world of activity. Emphatically championing, and striving to advance the academic knowledge base, Yerxa (2000) described occupation as:

> *"… What humans do when they act as agents of their own intentions in order to achieve a goodness of fit with their environments"* (Yerxa, 2000, p. 91).

This explains the enterprising use of occupation, combined with personal capacities to influence and contribute to meaningful environments. Yerxa (1998) earlier purported that humanity's innate drive for occupation is intricately linked with life satisfaction and health (Yerxa, 1998). When health is viewed through this lens, Yerxa proposes that the acquisition of skill will generate a public, positive view of capability, reducing stigma and celebrating people with impairments as equal and healthy citizens (Yerxa, 2000).

Additionally, Clark (1997) reflects on the erosion of biologically driven occupations, as humans become increasingly motivated by money and power, navigating increasingly fast paced, complex, modern life. She champions OS as fundamental in redesigning these ecologically harmful lifestyles, harnessing research from within it and other disciplines to articulate the impact of tempo and temporality

of occupation. The former describes the pace at which occupations are performed with Clark (1997) drawing comparisons between the quality of experience in fast and slower paced performance. The latter refers to the level of meaning implied by immersion of occupation in specific tenses across time. Both concepts are integral to understanding how occupations are distributed (Clark, 1997). Further the concept of *"occupation-temporality"* introduced by Zemke and Clark (1996) explains how occupation and time are interrelated, with occupation capable of influencing the amount and perception of time (Larson & Zemke, 2003; Zemke & Clark, 1996). Larson and Zemke's (2003) literature review illustrates the social coordination of time through occupations such as work and family life, highlighting the complexity of this orchestration. Several variables impact successful synchronisation including pace, rhythm, beliefs, constraints and compatibility of schedules (Larson & Zemke, 2003). Hocking (2000) proposes a framework to analyse the accumulated insights of OS describing first and foremost the phenomenon of occupation. She distinguishes occupation's common elements as:

> *"…. culturally, temporally and ecologically contextualised, and that it has a purpose or goal which may differ from perceived cultural ideas of its purpose. It is understood to be subjectively experienced and the product of human capabilities"* (Hocking, 2000, p. 61).

She reflected on the shift from understanding biologically driven occupation to occupation which is shaped by culture including gender, religious and political influences (Hocking, 2000).

In summary occupation is integral to our humanity. Our biological blueprints drive development using our capabilities to draft and redraft occupational stories as we encounter influential life experiences. It is dynamic (Nelson, 1988; Wilcock, 1993), situated in time (Clark, 1997; Larson & Zemke, 2003; Zemke, 2004), subjectively experienced (Hocking, 2000; Pierce, 2001) and universal (Yerxa, 2000). Further, occupation involves complex interplay between the person, their chosen occupations and environments (Hocking, 2000, 2009; Jackson, 1996; Wilcock, 1999;

Yerxa, 1998; Zemke & Clark, 1996). However, I am undertaking this study with the knowledge that theoretical underpinnings of occupation continue to evolve as research accumulates and diversifies. As OS supports the current research, I aim to add to the growing body of knowledge exploring the role of occupation in impacting health. Methods adopted capture, from the perspective of people with mental health disabilities, the types of occupations they participate in, the meaning attached to these and the environments in which they are situated.

2.4 Participation and Health

The OS literature I have discussed thus far describes humanity's need and drive for occupation, as enacted by the person in a meaningful way to influence their health. I will now define the concept of participation within OT and OS. I will also discuss how participation relates to health, considering its position within disability and human rights perspectives.

2.4.1 Introducing and Defining Participation within Occupational Therapy and Occupational Science

Hocking (2000) utilised the term occupational processes to explain the dynamic interplay of the person and their environment in the pursuit of meaningful performance, referring to Nelson's (1988) terminology to explain this interaction. However, the ambiguity that Nelson (1988) raised appears to continue, with vague and interchangeable terminology of engagement, performance and participation commonplace when describing occupation. Laliberte Rudman and colleagues (2008) queried the benefit of diverse definitions, wondering if the disciplinary culture is more powerful in determining a shared vision rather than terminology alone. Despite the issues articulating this concept, participation is upheld as a primary goal of OT (Law, 2002; WFOT, 2012; AOTA, 2014) as articulated by the American Association of Occupational Therapists (AOTA) in the following:

> *"Achieving health, well-being, and participation in life through engagement in occupation is the overarching statement that describes the domain and process of occupational therapy in its fullest sense"* (AOTA, 2014, p. S4).

Reflecting on this statement, participation, like health, appears as the function or outcome of engagement in occupation rather than a process or transaction. Price and Miner (2007) in their qualitative study using observational methods with a single occupational therapist, summarised that occupation-based intervention was complex, requiring multiple therapeutic strategies to collaborate in *"meaning making"*, enabling participation. They identified prominent strategies of *"doing with"* to facilitate successful experiences with the child's social environment (Price & Miner, 2007). Significantly, the authors identified a theme of *"pushing participation"* which encapsulated the therapist's combined use of praise, expectation and prompting to promote participation in occupation (Price & Miner, 2007). Whereas Moloney and Rohde (2017) described use of *"grading and adaptation"* (p.102) of exercises to support participation of men with a diagnosis of psychosis, during an Irish community-based football occupational therapy group. Law attempted to clarify the term participation, defining it as: *"…. involvement or sharing, particularly in an activity."* (Law, 2002, p. 641). This definition has been cited by OT and OS publications exploring the concept of participation with various groups and individuals (Borell, Asaba, Rosenberg, Schult, & Townsend, 2006; Lipskaya-Velikovsky, Jarus, Easterbrook, & Kotler, 2016; Nicklasson & Jonsson, 2012; Sakiyama, Josephsson & Asaba, 2010). Law (2002) situates occupation or it's derivative *"activity"* within a social context, implying collaboration within a shared purpose, or transaction between person and environment through occupation. Perhaps the use of activity in this way, offers an easily understandable term to illustrate a complex phenomenon (Pierce, 2001). Law (2002) elaborates, connecting participation to personhood and transformation:

> *"Participation is a vital part of the human condition and experience – it leads to life satisfaction and a sense of competence and is essential for psychological, emotional and skill development"* (Law, 2002, p. 641).

However, further research of the concept of participation continues. Specifically, its relatedness to OT (Vessby & Kjellberg, 2010), particularly in capturing the experiences of people with a mental health disability (Sakiyama, Josephsson & Asaba, 2010) and to contribute to its conceptualisation (Bartolac & Sangster Jokic, 2018; Larsson-Lund & Nyman, 2017). For example, exploring how participation was adopted within published OT research papers, Vessby and Kjellberg (2010) conducted a literature review across 38, methodologically diverse studies, using qualitative manifest content analysis. Three prevalent foci of participation were revealed: Client centredness, involvement in the environment and meaningfulness (Vessby & Kjellberg, 2010). Eleven studies were found to connect with client centredness, specifically client involvement in therapy, through decision making, collaboration and planning for change. Nineteen studies linked environment with participation in its potential to enable and restrict interactions with physical and social contexts. The remaining 23 studies revealed a connection between participation in meaningful occupations and enhanced quality of life or wellbeing. In summary, possibility for participation is enabled by client centredness, environment and meaning.

Participation is a term occurring in OT theoretical and practice models (Larsson-Lund & Nyman, 2017), evident within the Model of Human Occupation (MOHO) (Kielhofner, 2002). Within this model, Kielhofner (2002) identifies the term occupational participation as consistent but distinct from the ICF (WHO, 2001) definition. He defines it as:

> *"... engagement in work, play, or activities of daily living that are part of one's sociocultural context and that are desired and/or necessary to one's well-being"* (Kielhofner, 2002, p.115).

The word engagement is employed to describe the person's interactions with situated occupational forms. Recalling Yerxa (1980), Kielhofner (2002) distinguishes both the performance and personal experience of engagement, concluding: *"…. occupational participation connotes doing things with personal and social significance."* (Kielhofner, 2002, p.115). Credence is bestowed upon the personal and social value of occupation in the above definition of participation. However, as discussed earlier, occupation alone embodies cultural and personal meaning and so combining occupation with participation in this way may be superfluous. Indeed, Larsson-Lund and Nyman (2017), note how the presence of multiple terms may obscure the core focus on occupation in OT and OS, considering how participation may be one of these terms. Attempting to understand this further, the authors compared the ICF definition of participation while reviewing the concept of participation within three prominent OT practice models including the MOHO (Larsson-Lund & Nyman, 2017). They reconfirmed the presence of theoretical ambiguity, in relation to the conceptualisation of participation and concluded that this warrants further exploration. However, they proposed several questions in relation to how participation is adopted within OT theory, specifically highlighting a need to consider the wider definition of participation offered by the ICF, encompassing broader contextual issues such as citizenship (Larsson-Lund & Nyman, 2017). Speaking from a Swedish context they consider that participation may not be understood in the everyday lives of clients and alternative wording may be needed. Additionally, they identify terminology as confusing, citing different meanings inherent in *"participating in occupation"* as compared to participation (Larsson-Lund & Nyman, 2017).

Yerxa (1980) called for a *"mutual cooperation model"* between therapists and their clients, enabling collaboration and resisting more dominant discourses, consistent with the concept of client centredness discussed in later literature (Hocking, 2017; Law et al., 1995). This duopoly of intention is portrayed in the findings by Kjellberg, Kåhlin, Haglund and Taylor (2012), exploring participation and client centredness from the perspective of occupational therapists. Findings gleaned from questionnaires revealed most client-therapist relationships were characterised

as interdependent, despite therapists reasoning that independence in participation was the optimal goal (Kjellberg et al., 2012). The occupational therapists surveyed were attentive to participation as an outcome of therapy but tended to place restrictions in participation as the client's responsibility, with the authors asserting a need for review of client centred practice (Kjellberg et al., 2012). Thus, OT values continue to be threatened by discrepancies in practice.

In summary, participation as conceptualised within OT and OS is complex, often process driven and important to examine closely in relation to how it represents personal experience and relates to core concepts such as client centredness. I will examine participation from a disability perspective in the following subsection.

2.4.2 Introducing and Defining Participation from a Disability Perspective

The preamble to the 1948 United Nations Declaration of Human Rights recognised:

> "... *the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world*..." (UN 1948).

Although intending to uphold the rights of all people, their vast application and resultant inconsistent interpretations, perpetuated a culture of exclusivity for disabled people, with widespread discrepancies in advancing global policy and research in disability studies (Harpur, 2012). Assumptions regarding the individualistic nature of disability have historically imbued society, restricting participation of disabled citizens and encouraging rehabilitation to house disability within the person (Jongbloed & Crichton, 1990). Directly challenging the negativistic assumptions inherent in the medical model, a socio-political or social model of disability emerged (Jongbloed & Crichton, 1990). In the United States of America, the Independent Living Movement (ILM) was formulated to distinguish the segregation of disabled communities and uphold the right to participate (Franits, 2005; Hurst, 2003; Piškur et al., 2014). The slogan *"Nothing About Us Without Us"* has become

synonymous with the movement, necessitating the key stakeholders in any decision making concerning the actualisation of their rights (Franits, 2005). Prior to the emergence of the ICF, AOTA stated that occupational therapists are distinctive in their ability to support the ILM given their knowledge of the confluence between the person and their environment (AOTA, 1993).

The recognition of the environmental responsibility for creating disability was pivotal in shifting the classification toward a rights-based approach to understanding and implementing disability health policy and services (Hurst, 2003). Many occupational therapists collaborated on the development of the ICF (Law, 2002), however, the amount of involvement of those with disabilities was inconsistent, due to limited status and resources (Hurst, 2003; Hammel et al., 2008). Participation is defined by the ICF as *"involvement in a life situation"* (WHO, 2001, p.10). Hurst (2003) noted the ICF was welcomed in its revising of the descriptions of environmental dimensions creating disability, noting these can be used to determine barriers to participation. Further, she describes how disability is defined by the ICF as the results of interactions between impairment, functioning and environment. However, Hurst (2003) also acknowledges the ICF is a compromise (Hurst, 2003). Additionally, the ICF does not fully align with the Disability Rights Movement, with difficulty separating the environmental and personal domains, and activity and participation domains (Hammel et al., 2008; Mallinson & Hammel 2010). Further its focus on acting, has been challenged as to whether this minimises the subjective experience of participation (Hemmingsson & Jonsson, 2005; Sakiyama et al., 2010; Piškur et al., 2014; Bartolac & Sangster, Jokic 2018), while it has also been critiqued for its *"conceptual ambiguity"* (Hammel et al., 2008, p. 1446). For example, Hemmingson and Johnson (2005) propose that it offers a somewhat simplistic, and only interactive explanation of the relationship between person and environment. However, participation within the ICF has gained considerable momentum within the healthcare arena as demonstrated by its adoption in many research studies, educational programmes and its establishment as a priority goal for rehabilitation services (Hurst, 2003; Larsson-Lund & Nyman, 2017).

2.4.3 Introducing and Defining Participation from a Rights Perspective

From within OS, occupation is upheld as a human right (Galheigo, 2011; Hammell, 2017; Townsend, 2012; Townsend & Wilcock, 2004), while mental health is a universal human right (Townsend, 2012; UN, 2017; WHO, 2010). People with mental health disability have repeatedly been denied their rights through deprivation such as loss of freedoms, choice (Wallcraft & Hopper, 2015) and denial of true citizenship (Hamer, Kidd, Clarke, Butler & Lampshire, 2017). In its position statement on mental health, WFOT recognises:

> *"Globally, the high prevalence of mental health problems significantly affects participation in school, work, family and leisure pursuits that are all important for the inclusion and contribution to the socio-economic fabric of families and the community"* (WFOT, 2019, p. 2).

The UN Report of the United Nations High Commissioner for Human Rights, Mental Health and Human Rights (2017) found that the obstacles facing people with users of mental health services, those with mental health conditions or those with psychosocial disabilities are extensive including stigma, discrimination and marginalisation. They determine that human rights should be embodied within mental health policy to rectify these issues (UN, 2017). Efforts to transform thinking and practice within health and society toward people with mental health disability include the adoption of the Recovery Model within pertinent mental health policies amplifying person centredness and collaborative service development and delivery (HSE, 2018; Lal, 2010; Lloyd et al., 2008; UN, 2017). From the perspective of users and survivors of mental health services, Wallcraft and Hopper (2015) consider various models of disability including the Medical Model, Social Model, Disablement Model, the ICF and finally, the Capabilities Approach (CA). They determine that the capabilities model offers a rights-based model adept at challenging the dominance of the medical model and its conceptualisation of disability (Wallcraft & Hopper,

2015). Although the authors determine similarities between the CA and the ICF, they note that the ICF, needs to articulate how a person's financial resources can exacerbate disability in order to fully realise its understanding of "impairment". They highlight the CA as one in which capability could be restored following persistent deprivation in choice, opportunities, and participation (Wallcraft & Hopper, 2015).

Attempting to alter the impact of dominant discourses, within her critical examination of the construction of disability within OT practice, Phelan (2011) urges us to become *"more socially responsible practitioners"* (p. 167). This resonates with Yerxa's (1980) earlier assertion for ethical responsibility in the construction of disability. She acknowledges that often diagnosis is necessitated to access services which uphold the right of the children with whom she works, to societal participation (Phelan 2011). Answering Phelan's call to affect the just treatment of all abilities within society, is the growing exploration of participation from community, societal and political perspectives within OS (Balliard, 2016; Hammell, 2017; Kantartzis & Molineux, 2017; Townsend, 2012).

2.5 Literature Review Part Two: Analysing Key Concepts within Health, Occupational Science and Human Rights Discourses

In the remainder of this chapter I will explore health, OS and human rights dialogues as they specifically relate to mental health disability. I will highlight through relevant examples, how the presence of occupation and participation can empower and enable, while their absence creates injustice and disability.

2.6 Recognising the Interrelatedness of Occupation and Health

The relationship to health is articulated by Wilcock (1993) in the following quote:

> *"People need to make use of their capacities through engagement in individually motivating and ongoing occupations, and if they are able, or encouraged to pursue this need, they will, apart from supplying sustenance for survival and safety, enhance their health"* (Wilcock, 1993, p.22).

Expanding, she stresses that our very existence depends on our ability to engage in occupation (Wilcock 1993). A new definition of health was envisioned by Yerxa (1994), as she documented rapid advances across changing global health landscapes and populations. Later, she too called attention to the formative years of OT, imploring occupational therapists and occupational scientists alike:

> *"....to reaffirm that engagement in occupation, rather than being trivial, is an essential mediator of healthy adaptation and a vital source of joy and happiness in one's daily life"* (Yerxa, 1998, p. 417).

Both authors' use of the term engagement implies variable patterns of participation, ensuring all people regardless of their health status can benefit from occupation, departing from the medicalised impression of health or *"merely the absence of pathology"* (Yerxa, 2000, p. 89). The utility of work, specifically more physical employment, in maintaining health and vitality is paramount, with growing health concerns anticipated in the advent of an increasingly automated world (Wilcock, 1999; Yerxa, 2000), alongside the trivialisation of non-work occupations and societal overvaluation of excessive productivity (Wilcock, 1993, 1999; Yerxa, 1998).

Occupational science explains how we understand identity as it relates to participation in occupation, with occupation shaping our past self, offering stability during changing life demands, and informing our future selves (Zemke & Clark, 1996). For example, through the analysis of a specific client-therapist session, Jackson (1998) articulates the use of occupation in facilitating a client's rewriting of their

evolving occupational story in response to disability (Jackson, 1998). Traditional forms of recovery measured through gains in performance are challenged, typically delivered in contrived environments, pandering to institutional or political demands (Jackson, 1998). Instead, therapy through occupation offers an integrative view of the person as a capable occupational being (Jackson, 1998).

This assertion is shared by Laliberte Rudman (2002), in presenting the findings of three qualitative studies from her secondary qualitative analysis, elucidating the relatedness of occupation to wellbeing. She finds similarities across the three groups of participants (specifically groups of older persons, mental health consumers and caregivers) in relation to changing identity in the face of altering life circumstances. Commonalities such as the type and pattern of engagement in occupation emerged, with identity pronounced, cementing occupation as a defining personal attribute (Laliberte Rudman, 2002). The powerful impact of access to or denial of occupation permeated their narratives, tightly fastening it to identity. Additionally, Laliberte Rudman (2002) introduced the term occupational possibilities to describe:

> *"…. The ways and types of doing that come to be viewed as ideal and possible with a specific sociohistorical context, and that come to be promoted and made available within that context"* (Laliberte Rudman, 2002, p. 55).

This term imparts significance to the power of context in determining access to occupation and promoting participation. In summary, occupation offers a view of health that is not solely determined by the absence of disease. Understanding personal meaning attached to occupational choices and a person's occupational possibilities are significant in understanding their identity and ultimately how they respond to events within their life story.

On reviewing further historical and current health literature, Wilcock (2007), stresses the inseparable connection between occupation and health, as longstanding and well founded (Wilcock, 2007). She elaborates that the lack of a holistic understanding of occupation as it relates to physical, mental and social health, coupled with the delayed impact of the ICF, has perpetuated and accelerated the prevalence of *"social illnesses"*. Suggesting we *"go back to basics"* (p.3) to understand

this phenomenon, she asserts that occupation, perhaps attributable to its simplicity and banality, is underutilised in current health, social and political practices (Wilcock, 2007). In attempt to further the pursuit of generating knowledge about the *"form, function and meaning"* of occupation (Zemke & Clark, 1996, vii), Wilcock (2007) reflects on the gains made through smaller studies, qualitative in nature and varied research pursuits. In the following two subsections, I will attempt to elucidate the "*form, function and meaning"* of occupation to explain how occupation relates to health, specifically mental health. I will also return to Wilcock's (1999) synthesis of occupation as doing, being and becoming, to review its evolution.

2.6.1 The Form, Function and Meaning of Occupation within a Mental Health Context

Hocking (2009) cautions against accepting theory without robust examination of specific occupations, determining that knowledge of each unique composition will enhance OT applications. In detailing three occupations, Hocking (2009) uses the term occupation to distinguish the *"things that people do"* from the experience of doing. She notes additional phenomena influencing participation, including cultural variability and change processes, coupled with the pliability of the occupation itself (Hocking, 2009). Through advancing theory and research in this way, Hocking (2009) asserts that occupational therapists will be more clinically skilled and have greater understanding of engagement in occupation (Hocking, 2009). Additionally, Pierce (2001), attempting to detach, the two theoretical constructs of occupation and activity, highlights key distinctions. Firstly, the subjectivity or the personal experience attached to occupation and the collective cultural idea of activity. Secondly, the importance of context in creating specificity in time and place for occupation and the general or more flexible notions of context attached to activity (Pierce, 2001). She asserts that, clarity of these constructs will support occupational therapists in discerning each individual client's unique experience of occupation and situating occupation. Further, affording more opportunities for authentic, community-based OT practice, while tasking therapists to readily update their knowledge of typical, culturally and generationally relevant activities (Pierce, 2001).

One example of research of the form, function and meaning of occupation is that of Townsend's (1997) paper, reflecting on two ethnographic studies researching OT's work in mental health clubhouses, and the specific occupation of research within this setting. She identifies the occupations undertaken and the environment in which they are located (Townsend, 1997). She discusses the need to extend focus beyond the individual, to explain how occupation can transform both personal and social worlds. She adopts the term "*active process of occupation*" to describe how human beings live through their enactment of everyday occupation. She juxtaposes this against the restrictive interpretation of occupation presented by the economic market and social disempowerment (Townsend, 1997). Specifically focusing on the mental health clubhouse model, she describes the transformative features of occupation as: *"learning, organizing time and place, discovering meaning and exercising choice and control*" (Townsend, 1997, p.20). In her example, the occupations created by clubhouse members depicted as *"learning through active doing"* through their adoption of researcher roles, generated further opportunities for participation against the backdrop of reconfigured policy and service operation. She highlights how the individual and society are conjoined, conjuring images of a more inclusive society, appreciative of occupation beyond its economic contribution, and details the transformative effects of occupation in reimagining both person and society (Townsend, 1997).

Conversely, OS research concerning the function of occupation in mental health recovery (Lin, Kirsh, Polatajko, & Seto, 2009; Nagle et al., 2002; Sutton et al., 2012) doesn't portray occupation as *"active"* as described by Townsend (1997). Illustrating this, for example, is Nagle, Cook and Polatajko's (2002) study exploring the occupational choices of persons with diagnoses of schizophrenia or schizoaffective disorder, outside of paid employment. They found that participants reflected on the impact of emerging illness on the pursuits of their life goals, forced to disband these plans and develop altered, more achievable occupational trajectories (Nagle et al., 2002). This was most often experienced as the loss of paid, competitive employment. When reflecting on the present, participants chose occupations that fit their interests and current abilities, for one participant this was beginning chess. Participants expressed their agency in occupational choices based

on resources and self-awareness, despite differing from pre-illness aspirations (Nagle et al., 2002). Occupations were chosen by participants to:

> *"…. Provide them with money to fulfil their needs and wants, would help them feel better, would be fun, would increase and strengthen their social network, and would fill their days with things to do"* (Nagle et al., 2002, p. 76).

The authors found that participants recognised the relationship between their occupations, health and connectivity with others, for example, the amount of occupations chosen could promote or diminish health (Nagle et al., 2002). Additionally, they found that participants sought, amongst others, occupations that were *"purposeful, educational, interesting and fun"* (p.80). A desire for recognition and encouragement from others for their chosen occupations and not disapproval for those unchosen, and the impact of available of occupations and personal readiness to pursues these was a further finding (Nagle et al., 2002). Thus, occupational choices were an important determinant of health and connectivity with others.

Furthering this argument, are the findings from a phenomenological study by Sutton, Hocking and Smythe (2012) exploring experiences of occupational engagement for participants who self-identified as being in recovery from mental illness. Their findings depict four stages of engagement: "*disengagement, partial engagement, everyday engagement and full engagement"* (Sutton et al., 2012). The authors describe the spectrum of occupation needed to respond to the fluid form of the recovery process and the utility of occupation in facilitating choice and varied access. For example, disengagement was often essential to escape, describing a state of withdrawal and seeking refuge from their everyday worlds (Sutton et al., 2012). One participant identified this state as lying in bed continuously, with their sense's shutdown. In partial engagement, manageable amounts of occupation were used to aid reconnection with their worlds, including simple occupations such as drawing. In this state the process of engagement was the priority, and not the outcome, offering

participants a sense of time, space and experience of being. Progressing to *"everyday engagement"* involved:

> *"….. having direction, having increased commitment, clarifying and meeting expectations, and synchronising with others' time and space"* (Sutton et al., 2012, p. 145).

Finally, in full engagement participants reported feelings of complete *"rightness"* with what they were doing and their place in the world (Sutton et al., 2012). This starkly indicates from a subjective perspective, the role of occupations in helping and hindering the recovery process, while also highlighting the importance of choice in determining which occupations enable being (Sutton et al., 2012). Occupations were chosen for reasons of interest, health, purpose, connectedness with others and the world and in fulfilling responsibilities (Sutton et al., 2012). In summary the forms of occupation can differ, but choice is essential in offering varied possibilities for participation for people with a mental health disability.

Carlson, Park, Kuo, and Clark (2014), amongst other dimensions, describe occupation as a *"servant"*. Elaborating, that occupations are used by people for the purpose of advancing health, for survival, to achieve goals, experience meaning and sustain personal identity (Carlson et al., 2014). Through the following examples I will discuss the function of occupation in creating meaning and identity. For instance, introducing his lecture exploring the relationship of occupations to identity, meaning and overall life satisfaction, Christiansen 1999, differentiates health from wellbeing:

> *"Health enables people to pursue the tasks of everyday living that provide them with the life meaning necessary for their well-being*" (Christiansen, 1999, p. 547).

Expanding, he distinguishes that the primary aim of OT is wellbeing and not health. Reflecting on the relatedness of occupation to identity, Christiansen (1999) discusses

four propositions: identity is influenced by psychological constructs related to the self and by wider society, it is linked to what we do and how we consider this as it affects our social world. Identity is foregrounded in our life story providing meaning and coherence, and lastly identities in their meaning and coherence, create a sense of satisfaction and wellbeing. He surmises that occupation through its doing, affords experiences of meaning, shaping identity and providing continuity to life stories, especially significant during periods of disruption, for example through disability or ageing (Christiansen, 1999). Further, concerning the social representation of identity, he articulates how our sense of identity extends outward through our interactions. Finally, he highlights OT as a profession equipped to offer a service of meaningful occupation enabling participation for those whose identities are under threat from disability, impairment or restriction (Christiansen, 1999). Thus, participation in occupations both creates and projects identity. For example, Moloney and Rohde (2017) in their Irish research study about the experiences of men with psychosis in participating in a community football group found that members of the group overall considered it a positive experience. Expanding, the authors detailed how one participant formed a new identity as a player, moving outside that of "patient". Football was also viewed as a mechanism through which to build a weekly routine and reduce time doing nothing.

Although *"maintaining an acceptable identity"* was a theme spanning all three studies, analysed by Laliberte Rudman (2002), the study concerning mental health consumers is particularly relevant to my research. Here the participants consciously used occupation as a means through which to return to their former selves prior to becoming unwell. Reflecting on one participant's experience, Laliberte Rudman (2002), presents how their identity expression was disrupted, when unable to participate in paid employment as she had done prior to her illness onset. The author advises that this analysis is limited in that the original studies did not intend to focus on the relatedness of occupation and identity (Laliberte Rudman, 2002). She cautions that results provide a *"tentative conceptualisation"* of this relatedness and proposes further research. Reflecting too the need to focus on how each construct shapes and is shaped by the other, offering insights into the types of ideal social identities impressed by the social environment on groups such as those with

disabilities and resultant impact on their occupational choices (Laliberte Rudman, 2002). Additionally, occupational possibilities are contextualised and moulded by both time and expectation. They are situated within socio-political realms and have the power to include and exclude based upon determined expectations for doing (Laliberte Rudman, 2010).

Other authors have conceptualised this relationship as *"occupational identity"* (Unruh 2004; Kielhofner 2004). Referencing Christiansen (1999), Kielhofner (2002) defines occupational identity as:

> *".... A composite sense of who one is and wishes to become as an occupational being generated from one's history of occupational participation"* (Kielhofner, 2002, p. 119).

Unruh (2004) references Christiansen's (1999) and Kielhofner's (2002) descriptions, calling occupational identity a *"composite of one's occupations over time"* (Unruh, 2004, p. 292). This is elaborated upon in her paper analysing observations with a single research participant in his occupation of gardening. A series of occupations and not just the single productive occupation were found to be meaningfully relevant in defining occupational identity across traditionally defined occupational categories of occupation. The participant's identity was formed over time and grounded within his unique cultural history and environments (Unruh 2004), reflecting that a person: *"…. may reject or adapt to social norms in constructing an occupational identity."* (Unruh, 2004, p. 292). Public and private arenas also shaped identity with some, deemed more socially acceptable to reveal to others, for example, paid employment tends to be more easily discussed because of its primarily public context. Finally, the participant attained meaning through all his occupations and not just paid employment. In summary, occupation is instrumental in identity construction but is also intricately intertwined with meaning (Christiansen, 1999; Laliberte Rudman, 2002; Unruh, 2004).

Through her research with a group of older adult healthcare advocates with varying disabilities, Jackson (1996) discussed their personal themes of meaning and the expression of these within participants' daily orchestration of occupations and

identities. These personal themes of meaning spanned past and current lives providing continuity to each participant's identity through their selection of significant occupations (Jackson, 1996). Hammell (2004a) too discusses the human drive for meaning in the context of *"biological disruptions"* with resultant disability profoundly altering life plans. Meaning, purpose, choice and self-worth are identified as key factors in contributing to quality of life following the disruption of disability (Hammell, 2004a). Further, Reed, Hocking and Smythe (2010) explored the meaning of occupation for a group of adults who experienced a recent disruption to their everyday occupations. Meaning was often hidden, only unveiled following obstruction to the routine practice of a valued occupation (Reed et al., 2010). Three interweaving components of meaning are identified: choosing occupations according to significance and priority, the changeability of meaning depending on connectivity with others and the opportunities arising or retreating (Reed et al., 2010). The following subsection addresses the evolution of the dimensions of occupation.

2.6.2 Dimensions of Occupation: Doing, Being, Becoming and Belonging

The dimensions of occupation of doing, being, becoming were utilised by Wilcock (1999) to expand our knowledge of occupation as a synthesis of all three, beyond that of just *"doing".* Rebeiro et al., (2001), added the further dimension of belonging (Hammell, 2004a; Hitch et al., 2014a). Hitch, Pépin and Stagnitti (2014a) analyse the evolution of these concepts, adopting the "Integrating Theory, Evidence, and Action" method to further define and understand them through the review of cumulative research since their introduction. The authors ascertain that doing and being are the most understood constructs while, becoming and belonging are lesser known, and as a result not adopted or researched as eagerly (Hitch et al., 2014a). The authors note that in Wilcock's theory, doing was conceptualised as both explicit and tacit (Hitch et al., 2014a). Affirming this, Gould, DeSouza and Rebeiro-Gruhl (2005), in their qualitative study with four men with schizophrenia, documented the impact of a significant mental health disability on each participant's life and their responses. The

term *"coasting"* was employed by the authors to describe the period when participants adopted a state of *"being",* highlighting simple occupation as a way of doing and becoming normal again (Gould, DeSouza & Rebeiro-Gruhl, 2005). Additionally, the study mentioned earlier by Sutton et al. (2012) documented how occupation was used by participants to achieve a state of being during periods of *"disengagement".* Hitch et al. (2014b) assert that being must be addressed with OT practice for clients with mental health problems, to ensure client led engagement in meaningful occupations. Expanding the understanding of belonging, is Blank, Finlay and Prior's (2016), qualitative study using interpretative phenomenological analysis, to explore the lived experience of people with mental health and substance misuse problems. The concept of belonging too is distanced from that of doing, in that participants did not link feelings of belonging with specific engagement in occupations, but instead with meaningful places where they connected with others (Blank et al., 2016). Considering that occupational engagement may be a lesser priority, Blank et al. (2016) note the legitimacy of withdrawal or graded levels of doing in managing mental health needs.

Hitch et al. (2014b), attempt to expand the understanding of their interrelatedness during occupational engagement. They caution of the unexplored terrains of doing, with some emerging research considering the harmful impact of occupation (Hitch et al., 2014b). Since, Hitch and colleagues' (2014a; 2014b) research, Chisman and Brooks (2018), in their grounded theory study investigating dimensions of being and belonging through meditation, discussed the use of meditation by participants to both understand themselves and connect with others. The authors supported other literature that described the role of restorative occupations or those performed alone, not as separating from others but as bettering relationships. Findings indicated the relatedness of the concepts of being and belonging (Chisman & Brooks, 2018).

The literature discussed above is compelling in detailing occupation's stance in affording health and wellbeing, as it unfolds suffusing life with meaning and moulding identities. However, occupation does not always involve overt doing to

meet these needs. Although the personal viewpoint is essential in defining occupation, so too is the environment. The following section examines this relationship in greater detail.

2.7 The Significance of the Person, Occupation and Environment Relationship

Participation is a concept widely used within OS as well as across other disciplines and movements, for example within global health through its adoption in the ICF (WHO 2001) and within disability research (Hamell, 2008; Durham, Brolan, & Mukandi, 2014). Understanding participation is key in identifying how the rights of people with disabilities are upheld through inclusion or when injustices occur, and exclusion prevails (Hocking, 2017; Bartolac & Sangster Jokic, 2018). In this next section I will discuss literature pertaining to participation within the academic discipline of OS.

2.7.1 Conceptual Discourses within Occupational Science

Traditional theoretical OT models are concerned with the confluence between person, environment and occupation (Larsson-Lund & Nyman, 2017) and although models differ, they all tend to discuss occupation and occupational performance (Whiteford et al., 2000). Law et al. (1996) discussed the evolution in OT practice toward a transactional view of occupational performance, whereby the individual is bound to context, and continually impacted by fluid temporal, structural and personal factors in their enactment of occupation in everyday life (Law et al., 1996). They proposed the Person Environment Occupation (PEO) Model as a practice model to understand the dynamic interplay of all three components in creating occupational performance (Law et al., 1996). Within the PEO significant attention

was drawn to defining and recognising the importance of the environment in hindering or promoting occupational performance (Law et al., 1996). Additionally, Whiteford and colleagues (2000) reflect on the evolution of the Canadian Model of Occupational Performance (CMOP), altering occupation so that it is foregrounded, dynamic and interconnected with context. Reflecting a revival of occupation within theoretical OT models, the CMOP views occupation as situated, places the person and their spirituality at its core, indicating how each person is impacted by and impacts their environment while conveying spirituality through meaningful occupation (Whiteford et al., 2000).

Some have critiqued these models, noting that occupation, as contained within defined parameters is constricted by its relation to the person, or solely as a conduit between person and environment (Dickie et al., 2006; Fogleberg & Frauwirth, 2010). For example, Dickie and colleagues (2006), in their critique of individualism or the perceived location of occupation solely in individual experience, proposed a reconceptualization of occupation within OS. Identifying the *"dualistic view"* of occupation and context as separate entities, they propose divorce (Dickie et al., 2006). They purport deconstruction of the perceived barriers between these two concepts, may serve to integrate understanding of occupation (Dickie et al., 2006). Similarly, Fogleberg and Frauwirth (2010), in their examination of the evolution of systems theory within OS, echo the stance of Dickie and colleagues (2006) regarding apparent individualism. They cautiously propose a model of complex systems theory highlighting the term *"distributed systems"* to extend our view beyond individuality, referring to collective enactment of occupation. A mixed heterarchical and hierarchical system is described to conceptualise the multi-layered and transactional view of occupation distributed across population, community, group and individual layers research (Fogleberg & Frauwirth, 2010).

However, Wilcock (1993, 1999) and Yerxa (1998, 2000) located the individual within their environments, while others specifically mention the cultural situatedness of occupation (Hocking, 2000; Jackson, 1996; Zemke & Clark, 1996). Additionally, Zemke (2004), in her discussion about time, space and occupation, situates humans within and moving through space by their occupational

engagement, and determines: *"We are embodied, spatially dimensional as well as temporally"* (Zemke, 2004, p. 612). Through this movement we are constantly exchanging with our environments, shaped by it and experiencing a sense of space and time through it (Zemke, 2004). Thus, person and environment are of equal importance in understanding participation. The idea of transactionalism continues to be contested, with Pierce (2009) rebutting the discourse of the growing distance from individualism in conceptualising occupation, detailing the harmful impact to the core tenets of OS. She advocates for a more rational approach via further contributions to this continually evolving discipline, specifically a measured approach to capture both the health promoting and detracting elements within the definition of co-occupation (Pierce, 2009). Further, Kuo (2011) cautions of polarisation between individualism and transactionalism within OS, discussing the relatedness of occupation to a perpetually evolving world, as a person relates to their world through a stream of responsive actions, shaping their experience and fastening them closer to it. She concludes that occupation, when considered across past and potential future experiences, can yield health promoting choices which can transcend present limitations (Kuo, 2011). However, she notes that the past is subject to biased and often faulty memory with the future unpredictable, identifying the need for resilience as well occupation in managing unforeseen challenges (Kuo, 2011).

Carlson et al. (2014) also debate the dialogue of individualism and transactionalism in OS. Focusing on how occupation is determined from an individual perspective, the authors elucidate the significance of this relationship in presenting the dimensions of occupation as they relate to the self (Carlson et al., 2014). Summarising the cumulative impact of these occupations, attesting that occupation itself is *"a playing field"* moulding personal development and resultant life experiences as a person *"transacts with the world"* in their everyday life (Carlson et al., 2014, p. 124). While acknowledging, the limitations in considering solely the personal view of how occupation is experienced, they purport that increased knowledge is warranted about occupation as it relates to identity and self, both from the personal perspective and from a transactional view (Carlson et al., 2014).

Research pertaining to the understanding of occupation from a global experience, or from a macroscopic view, is promoted and advanced (Laliberte Rudman & Aldrich, 2017; Kantartzis & Molineux, 2017) with Reed and colleagues (2011) noting this as significant in furthering our understanding of meaning. Additionally, the need for more sensitive methods within qualitative research is argued to capture the transactional experience of occupation within varied contexts (Huot & Laliberte Rudman, 2015; Lynch & Stanley, 2017). In the next subsection I will explore the interconnectedness of people, their environments and chosen occupations.

2.7.2 Participation Situated within the Social Environment

Jackson (1996) asserts that the occupational choices we decide upon are not governed solely by personal preferences or sociocultural histories. A stance, echoed by Kuo (2011) who purports an inherited aspect to experience as shaped by an individual's existing in their unique worlds and sharing "*a collective sociocultural history that informs ways of being and doing"* (Kuo, 2011, p. 133). Within theoretical OT models, the environment is prominently placed, with physical, social, institutional and cultural dimensions addressed (Law et al., 1996; Whiteford et al., 2000). From the experience of people with mental health disabilities those aspects of the environment, social, cultural and institutional dimensions, appear to have the most significant impact on participation (Rebeiro, 2001; Townsend, 1997). Regarding promotion of recovery, societal interdependence is advocated in the form of mutual, trusting relationships, offering belonging and connectivity (Sakyiama et al., 2010). However, in contrast, the social environment can present significant challenges for those navigating mental health disability, in the form of stigma and discrimination (Hamer et al., 2017; Nagle et al., 2002; WHO, 2010).

Within her paper addressing social inclusion Hocking (2017) asserts occupation is *"socially determined"* (p. 34) by society's creation or removal of opportunities to do, consequently upholding or diminishing a person's right to occupation. Further, Hitch et al. (2014b) describe the multidimensional nature of

occupation. All four dimensions of doing, being, becoming and belonging coincide, across three levels: individual, group and population, summarising that:

> *"..... Engaging in occupation requires that we perform activities and occupations (doing) that meet the needs of both ourselves (being) and others (belonging), that we can learn from and build upon through time (becoming)"* (Hitch et al., 2014b, p. 258).

Occupation as socially situated emerges within several studies reviewed focusing on the experience of the environment from the perspective of those with mental health disabilities (Asaba, 2008; Rebeiro, 2001; Sakyiama et al., 2010). For example, Rebeiro (2001) in her secondary analysis of a series of research studies, focused on determinants of an affirming social environment for people with a mental health disability. Identifying three key elements: being with others with shared experience, affirmation of worthiness and finding belonging through safety (Rebeiro, 2001). Additionally, discussing group engagement in assembling and packaging of chopsticks, within a Japanese Psychiatric Hospital, Asaba (2008) illustrates socially enacted occupation. Despite clinical assumptions regarding the limited therapeutic gain of this institutional group, coupled with growing economic constraints, the participants' voices powerfully capture the meaning and value of this occupation to their personhood and connectivity with one another. Asaba (2008) describes how in Japanese cultures, interdependence and similarity afforded people the opportunity to partake in the rich meaning of a shared occupation. He posited this showcased occupation as socially situated, furthering our understanding of this concept within OS (Asaba, 2008).

Fortifying this link between identities and environments, Asaba and Jackson (2011) in their study of one individual's disability experience, highlight the profound effects of political and media surrounds. Through occupation, the participant navigates a changing identity, subject to shifting sociocultural influences, opening and closing occupational possibilities as he establishes his new identity (Asaba &

Jackson, 2011). These findings are significant in considering how the social and political environment can include or exclude membership. Further, in a series of provoking questions Laliberte Rudman (2010) challenged me to consider how government decision making and policy implementation, in concert with social structures influence the range of occupational possibilities and restrict diversity (Laliberte Rudman, 2010). Furthermore, Laliberte Rudman and Aldrich's (2017), findings from their critical narrative inquiry with people who described themselves as long term unemployed are relevant. Through obtaining participant narratives they sought to advance OS beyond the individual focus, by dissecting how powerful social and political discourses shape what people do and who they are (Laliberte Rudman & Aldrich, 2017).

Thus, the socio-cultural dimension of the environment would appear significant in enabling or restricting occupational participation. Further the literature reviewed above, addresses the importance of the social environment for creating occupational possibilities. In the next subsection, I will explore the concepts of co-occupation and collective occupation as they occur within a person's social environment as they interact with others through occupation.

2.7.3 Co-Occupation and Collective Occupation

Co-occupation was a term discussed within emerging OS, defined as those occupations requiring *"more than one person's involvement"* (Zemke & Clarke, 1996, p.213). Larson and Zemke (2003) highlight the effort involved in the *"synchrony"* of time to enable the successful coordination of occupations amongst social groups. Focusing on two different work professions, they highlight how an individual's experience of work is largely shaped by the work culture, the challenges of each worker's responsibilities and their own personal skills (Larson & Zemke, 2003). Significance continues to be attributed to the construct of co-occupation (Pierce, 2009). Co-occupation is conceptualised as accounting for the impact of the shared experience in changing both individuals as they connect through occupation (Pierce,

2009). Building on co-occupation, Kantartzis and Molineux (2017) consider occupation within community. Referring to the concept of collective occupation they describe inherently social occupations, reliant on continued transactions with others to form an identity of belonging (Kantartzis & Molineux, 2017). Collective occupation is conceptualised in three forms: informal daily encounters in public spaces, participation in civic society through organisations and associations and celebration and commemoration. The power of this environment in creating opportunities is captured in the following sentiment:

> *"The public world and being part of that world through collective occupation, was a unique source of opportunities and experiences"* (Kantartzis & Molineux, 2017, p. 175).

The authors caution of the duality of social networks in affording participation in only designated occupations with the power to exclude and stigmatise, noting the importance of considering this concept in OT practice when pursuing social change (Kantartzis & Molineux, 2017). A pattern identified in OT practice is the tendency to create supportive environments within the community for specific groups, however, the authors lobby the profession to consider their role in developing inclusive spaces for all citizens (Kantartzis & Molineux, 2017). Having explored the concept of participation in OS I will discuss participation from a disability perspective below.

2.8 Participation and Disability: Exploring Pertinent Perspectives

In 2006, the UNCRPD (UN, 2006) emerged following mounting pressure from the Disability Rights Movement to uphold their equal rights, dignity and diversity

(Harpur, 2012; Durham et al., 2014). Participation is enshrined as a right in the UNCRPD as demonstrated by Article 1: Purpose:

> *"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others"* (UN, 2006, p. 3).

In this section I will explore how these rights are operationalised in healthcare policy and practice within Disability research, OS and OT, as all fields strive for greater proximity to them.

2.8.1 The International Classification of Functioning: Does it offer a transactional view?

Disability as defined by the ICF is viewed under three categories: "*impairments, activity limitation and participation restrictions"* (Larsson Lund & Tamm, 2001) with disability arising in any one or all categories (Mallinson & Hammel, 2010). The ICF attempts to consider the biological and environmental interactions in understanding disability across the lifespan as evidenced by the centrality of the concept of participation (Hemmingsson & Jonsson, 2005), resultant from marrying the medical and social models of disability (Levasseur, Desrosiers & St-Cyr Tribble, 2007; Larsson Lund & Tamm, 2001). The adoption of the social model of disability was a significant change in upholding a rights-based approach (Hurst, 2003).

The ICF was designed to understand functioning in two ways: body structure and function and activity and participation (Mallinson & Hammel, 2010). Activity is defined as *"the execution of a task or action by an individual"* with activity limitations defined as "*difficulties an individual may have in executing activities"* (WHO, 2001, p.14). Nicklasson and Jonsson's (2012) research found that a person's ability to

perform activities was not related to participation requiring further research on this ICF domain. Not only personal capacity but the perceptions of others were found to be important for enabling participation (Nicklasson & Jonsson, 2012). Further, these components can be used interchangeably, gaining considerable criticism, with the ICF being rejected by some until these dimensions are delineated (Mallinson & Hammel, 2010; Piškur et al., 2014). Mallinson and Hammel (2010) note the use of transactive conceptualisations in OT to capture the complexity of the process of participation and the environmental conditions which support this. Viewed through this lens, the components impacting participation are considered equal in their influence promoting a more relevant and valued interpretation of disability (Mallinson & Hammel, 2010). They offer this approach or transactive model as a solution to the dilemma of measuring and acting on participation restrictions in a meaningful and client centred way when disabled people are accessing health services (Mallinson & Hammel, 2010). This holds significance in advocating for the role of OS and OT in transforming the wider understanding of health, as that which is more integrated.

The ICF currently considers social roles within the domains of activity and participation with Piškur (2013) attempting to define social participation separately to clarify the relationship between participation and the social context. However, challenging Piškur's (2013) perspective, is Bartolac and Sangster Jokic's (2018) research with adults with physical disabilities, examining the concept of participation. They found that participants identified both barriers and enablers to participation at an individual level, as well as contextual, including personal capacity and outlook, in addition to access to physical space and formal and informal social support (Bartolac & Sangster Jokic, 2018). They differentiate between the concepts of social participation and occupational participation but conclude that these are interrelated (Bartolac & Sangster Jokic, 2018).

In contrast to the ICF, the term social participation in the Disability Creation Process Model (DCP) represents 12 domains encompassing daily activities and social roles (Levasseur et al., 2007). This starkly represents the differences between the two, with the latter fully embracing the impact of the social world on creating

disability (Levasseur et al., 2007). Expanding on this, participants in one study described participation: "....*as a right that is predicated upon access, opportunity, respect and inclusion*" (Hammel et al., 2008, p. 1459).

In response to the ICF definition, disability activists asserted an expansive and complex understanding of participation, with the following themes identified: (1) *active and meaningful engagement*, (2) *control and choice*, (3) *access and opportunity*, (4) *personal and societal responsibilities*, (5) *having an impact and supporting others* and (6) *social connection, societal inclusion and membership* (Hammel et al., 2008). In examining several definitions in relation to social participation within social science, Bartolac and Sangster Jokic (2018) conclude that definitions, such as described above, are consistent with the perspective of disability as societally constructed.

2.8.2 Cultural Perspectives of Participation and Health

Participation is fundamental to both OT (Isaksson et al., 2007; Kjellberg et al., 2011; Law, 2002; Larson-Lund & Nyman, 2017) and the Disability Rights Movement (Hammel et al., 2008). The inclusion of participation in the ICF has received global recognition, and as a result, progressed rehabilitation (Cerniauskaite et al., 2011; Hammel et al., 2008) sharing it as a primary goal with OT (McLaughlin Gray, 2001; Vessby & Kjelberg, 2010). For example, Wilcock (2007) encourages occupational scientists to monitor the WHO's publications as potential areas for research given their continued attention to what people do, their subjective experience of this and how it contributes to their health. However, some have sceptically considered the perceived progress of the ICF (Borell et al., 2006; Hammell, 2004a, 2015). Demonstrating this, Galheigo (2011) discusses how globalising healthcare policy and its delivery, runs an increasing risk of discounting the cultural context and imposing non-meaningful, disabling practices.

Within OS, some authors assert that westernised ideals have been imposed, excluding scholars from the East and South from partaking in knowledge exchange and pivotal discipline developments (Galheigo, 2011; Kantartzis & Mollinuex, 2017),

influencing theoretical perspectives and clinical practice (Kantartzis & Molineux, 2017). For instance, Hammell (2017) highlights independence as emerging from the Western world, reinforced by the medical model, imploring occupational therapists and occupational scientists alike toward the reconfiguration of terminology to remedy this issue. Similarly, Durham et al. (2014) advocate for continued practice of critical reflexivity in research, with its absence silencing disabled persons' rights through misinterpretation of cultural issues and exposure to researcher bias (Durham et al., 2014). Further the presence of ableism may also impact participation for disabled people, defined by Hammell (2004a) as: *"... Social practices and relations that assume and privilege able-bodiedness"* (Hammell, 2004a, p. 297). For example, Lindsay, Chan, Cancelliere, and Mistry (2018), found, in exploring the experiences of youth with disabilities of volunteering, that balancing the demands of these responsibilities with looking after themselves and their health was challenging for participants. This contrasted with youths without disabilities who reported no such issue (Lindsay, Chan, Cancelliere & Mistry, 2018). This illustrates the hindrances to participation for people with disabilities, not present for those without disabilities, and is an example of ableism within a specific occupation. Hammell (2004a), like Yerxa (1994) asserts that realisation of capability through occupation, can create a conceptual shift for disabled people from disabled to able, denying social conventions.

Fransen, Pollard, Kantartzis and Viana-Moldes (2015) characterise citizenship simply as participation in society, as every person's right and responsibility. Citizenship extends beyond the individual to the sense of civic duty and related occupations to the wider cultural and social participation (Fransen et al., 2015). However, infringements on citizenship have long existed for the disabled community with lower rates of employment, access to housing and general participation and integration within their communities (Hurst, 2003; Galheigo, 2011; NDA, 2017; WHO, 2010). For example, Hamer, Finlayson and Warren (2014) chronicle mental health service users experience of citizenship, specifically their viewpoints on feeling excluded or included, through use of semi-structured interview. Emerging from this, were the demand to comply with social norms in order to gain fuller citizenships

through inclusion, but often efforts were in vain as states of exclusion persisted (Hamer et al., 2014). Harpur (2012) reflects that with the clarity and protection offered by the UNCRPD further progress in realising these rights is reliant on continued advocacy and effort. Consistent with the UNCRPD the National Disability Strategy Implementation Plan (National Disability Strategy Implementation Group (NDSIG) 2015) outlines specific plans to achieve key objectives in advancing the rights of disabled people in Ireland, chief amongst these is equal citizenship. Specific indicators guiding its achievement include collaborative development and implementation of legislation, disability awareness training and accessibility to information (NDSIG 2015).

To summarise, denial of disabled people's rights continues with the presence of ableism and infringements on citizenship. There is much to be done, nationally and internationally to protect and advance disabled peoples' rights to participation.

2.8.3 Participation and Mental Health Disability

Mental health is a right that continues to be threatened by historical and current health, social and political practices (Townsend, 2012). Some parallels can be drawn between the mental health Consumer Movement and the Disability Rights Movement, as consumers of mental health services in the 1980s began to share and publish their experiences of treatment and society (Rebeiro Gruhl, 2005). More recently, Russo and Wooley (2020) comment on the freedoms unfolding from the success of the social model of disability and consider how such a similar model could be effective for users and survivors. They acknowledge how the involvement of survivor activists in the formation of the UNCRPD upended the status quo, with survivors owning its formation, considering too how implementation of the UNCRPD will require collective effort (Russo & Wooley 2020). Discontentment with the focus on diagnosis and dependency on professionals who held fatalistic attitudes to prognosis were some of the issues propelling the consumer movement (Rebeiro Gruhl, 2005) toward the model of recovery. However, speaking now from the perspectives of service users and survivors within a current Irish context, Edwards

and Thomas (2018), comment on the mainstreaming of recovery. They consider how recovery has drifted from its ethos, becoming diluted by its use in professional settings with subsequent inattention to social and political influences (Edwards & Thomas 2018).

Despite its extensive adoption, recovery theory is difficult to consistently define, with a range of interchangeable descriptions used: recovery model, paradigm, framework, and principles (Lal, 2010). According to Lloyd, Waghorn and Williams (2008), recovery can be conceptualised in clinical, personal, functional, and social dimensions with all four encompassing a person-centred recovery assessment and model of care. The authors note that occupational therapists should be concerned with promoting social and functional recovery, particularly fostering social inclusion (Lloyd et al., 2008). Sutton et al. (2012) described recovery as transactional, in that this process of recovery unfolds within a person's daily life through their exchanges with their surrounding contexts. Environments which are supportive and offer a range of occupational choices are indicated to support the recovery process (Rebeiro, 2001; Sutton et al., 2012).

Additionally, a collaborative community service was found to be successful in using occupation to promote community connectedness leading to increased feelings of inclusion, self-worth, and wellbeing (Fieldhouse, 2012). The power of occupation, activity analysis and therapeutic use of self were deemed successful intervention strategies in promoting meaningful changes toward participants' wellness and overall health (Fieldhouse, 2012). However, Lipskaya-Velikovsky, Jarus, Easterbrook, and Kotler (2016) presented differing findings in their quantitative study exploring the objective and contextual participation patterns of people with schizophrenia. They found participants had more restricted participation patterns in occupations such as domestic life and leisure activities, with overall less frequent participation and greater time spent alone, when compared to those without schizophrenia (Lipskaya-Velikovsky et al., 2016). Offering insights from qualitative research, Sakiyama, Josephsson and Asaba (2010) illustrate the complex contradictions prevailing for one man with mental health difficulties attempting to participate in society. Eloquently describing through metaphors, his inner conflict in

regulating the amount of social support desired to participate, conflicting with his identity within Japanese culture (Sakiyama et al., 2010). He also highlights the daily challenges he navigated to protect his participation, starkly, the heightened challenges he perceived in participating in everyday occupation, comparing this to the *"Olympic games"* (Sakiyama et al., 2010). This rich narrative is significant in informing the current research, advancing the centrality of the lived experience in understanding participation.

In summary, participation is a significant concept within the fields of health, disability and OS. Its expression through policy is debated by those from various cultural perspectives, most importantly by the view of disabled people. Achieving full participation in society requires that human rights be upheld and realised through inclusive and just practices, which I will address in the following section.

2.9 Rights, Occupational Justice and Social Inclusion

Enabling the right to occupation is of primary concern to both OS and OT (WFOT, 2019). Equally, these rights are asserted within the arena of disability research and policy (Durham et al., 2014; Hammel, 2008; Hurst, 2003). Occupational Justice (OJ) is an important concept for this research given it provides necessary terminology to label and identify patterns of breaches to occupational rights while supporting responsive change to restore occupation (Hammell, 2017; Hocking, 2017; Townsend & Wilcock, 2004). Within this section, I will address important societal constructs of inclusion and exclusion, while considering how these are expressed through an OS lens in the form of occupational rights and OJ.

2.9.1 The Right to Occupation and Occupational Justice

Introducing the concept of OJ through their open dialogue, Townsend and Wilcock (2004) acknowledge their belief that humans are both occupational and social beings, with diverse capabilities and community backgrounds, needing varying levels of enablement to prosper. Believing that:

> *"…. Occupations are the practical means through which humans exert citizen empowerment, choice and control"* (Townsend & Wilcock, 2004, p. 80).

Within this dialogue they propose four occupational rights:

> *"To experience occupation as meaningful and enriching; to develop through participation in occupations for health and social inclusion; to exert individual or population autonomy through choice in occupations; to benefit from the fair privileges for diverse participation in occupations socially excluded from full citizenship without participation in the typical range of occupations o f a community"* (Townsend & Wilcock, 2004, p. 80).

These are reiterated in the occupational rights detailed by WFOT (2019) obligating occupational therapists to utilise client centredness collaboratively with those experiencing injustices to extinguish such experiences. Exploitation of the above rights can result in four identifiable states of participation injustice: occupational alienation, occupational deprivation, occupational marginalisation and occupational imbalance (Townsend & Wilcock, 2004; Nilsson & Townsend, 2010). Occupational justice is an evolving discipline within OS (Hamer et al., 2017; Nilsson & Townsend, 2010; Townsend & Wilcock, 2004), defined as:

> *".... an outcome of social policies and other forms of governance that structure how power is exerted to restrict participation in the everyday occupations of populations and individuals"* (Nilsson & Townsend, 2010, p. 58).

Thus, some people in society are afforded the opportunity to participate in occupations, while others are marginalised and restricted (Nilsson & Townsend, 2010). An example of one such injustice is that of occupational alienation, where people find themselves obliged to participate in occupations that are not meaningful to them, an experience that may be personally determined or collectively felt (Bryant, Craik & McKay, 2004; Townsend & Wilcock, 2004). For instance, Bryant, Craik and McKay (2004), in their review of a mental health day service environment which participants regularly attended, uncovered occupational alienation with specific individualistic and contextual dimensions. Occupational alienation could occur as a result of occupations imposed by the staff routine or attitudes within the day centre setting, leading to participants needing to conform because of fearfulness about potential exclusion from this setting or from care planning. Further participant's experienced occupational alienation from the dislocation of the service from the larger community. Finally, participants experienced a sense of belonging in being part of a group with their peers and for some getting support from staff contributed to this, a finding shared by Rebeiro et al. (2001) (Bryant et al., 2004).

2.9.2 Promoting Social Inclusion, Access to Occupation and Client Centredness

Harrison and Sellers (2008) in their opinion paper, highlight the profound impact of social exclusion for people with mental health problems, with social inclusion remedying this. For social inclusion to be realised, Harrison and Sellers (2008) assert that changes must arise both from the individual affected and the society in which they reside. Social Inclusion is described by Blank et al., (2016) as embodying personal feelings of belonging as well as physical interactions within the local context. Social inclusion policy has featured centrally within UK governmental policies (Blank et al., 2016; Harrison & Sellers, 2008). Within Ireland, the Government launched its Social Inclusion plan in 2006, targeting inclusion across the lifespan, aspiring to reduce exclusion for the most marginalised and vulnerable in Irish society (Government of Ireland, 2007). However, this has been challenged by disability activists noting a lack of specific targets for this population, particularly in relation to poverty, recreation and social activities (Webb, 2009). These findings are mirrored in the research of OS

with the concept of OJ key in understanding the role of occupation and participation in social determinants of health (Gupta, 2016). In her review of the evolving concept of OJ, Gupta (2016), summarises findings of research predominantly discussing experiences of injustices. Correlation between injustice and *"dissonance"* in OT practice was determined, largely due to pressing demands on practice resulting in adequate service delivery and distancing from professional values (Gupta, 2016). Chiming with Hammel's (2017) view, exhorting occupational therapists to acknowledge and circulate the relative concepts of occupation, wellbeing and rights, to fully recognise the dependency of participation on society in affording meaningful opportunities to contribute and belong (Hammell, 2017).

Alongside enablement, client centredness is a core tenet of OT theory and practice (Law et al., 1995; Hocking, 2017), readily adopted in professional identity however often purported to be used in practice but not clearly defined (Hammell, 2013; Law et al., 1995; Vessby & Kjellberg, 2010). For example, Law and colleagues (1995) attempted to elucidate concepts which indicated client centredness in OT. These are: client choice (autonomy), active collaboration between both client and therapist (partnership), working toward client determined goals (enablement), considering the context (contextual congruence), accessible and flexible service delivery and lastly, respect for diversity (Law et al., 1995). The authors recognise that obstacles can occur in realising client centredness, arising from within the person, the therapist or context (Law et al., 1995).

Comparisons between ICF and OT Assessment measures may further the ICF's utility as a practice model (Pettersson et al., 2012). However, Levasseur, Desrosiers, and St-Cyr Tribble (2007) discuss the lack of subjective satisfaction in using the ICF checklist, the primary mechanism for the implementation of this model. Disability and OT perspectives are aligned in their assertions that participation cannot be assessed without seeking the individual's perspective (Durham et al., 2014; Hammel et al., 2008; Nicklasson & Jonsson, 2012). Within OT, there exists an established use of narrative in assessments (Larson-Lund & Nyman, 2017). The importance of narrative is illustrated by Franits (2005) who describes the centrality disabled people in decision making and intervention planning, with objectivity in therapists'

interactions endangering client centred practices (McCorquodale & Kinsella, 2015). In pursuit of this, therapists should employ skilled communication and exposure to narratives of others, specifically narratives embodied by disability studies, as mechanisms to increase therapist efficacy and empathy (Fanits, 2005). Further, Vessby and Kjellberg (2010), propose interview, likely the most useful, and consistent method to measure participation, given its capacity to capture personal perspectives.

2.9.3 Threats to Inclusion

The ICF has further imbued OT with the notion of participation, as evidenced by its pertinence in conceptual and clinical practice (Kielhofner, 2002; Larson-Lund & Nyman, 2017; Vessby & Kjellberg, 2010). Some consistencies have been determined between OT conceptual models and the ICF (Harrison & Sellers, 2008; Larson-Lund & Nyman, 2017). Despite these advances, the ICF compromises a complete understanding of the complex phenomenon of participation, specifically the subjective experience (Borell et al., 2006; Hammell, 2015; Hemmingsson & Jonsson, 2005; Sakiyama et al., 2010). Additionally, the way the ICF conceptualises personal factors separately to the social world conflicts with the DCP (Levasseur et al., 2007). It is argued that the current state of ICF implies that the person and their environment must be separated to measure these as individual constructs (Hammel et al., 2008). Furthermore, Hammell (2004b), critically contests the ICF classifications, noting an inherent conflict through its perceived attempt to segregate those with disabilities. The author urges occupational therapists to employ scepticism and careful critique before welcoming ICF into practice (Hammell, 2004b).

McCormack and Collins (2010) describe realising client centred OT through aligning core principles of client centredness with theoretical concepts in Disability studies, including rebalancing power, communication, collaborative working, appreciation of client choice and upholding positive views of disability (McCormack & Collins, 2010). The ICF may advance our professional standing but conversely, diminish OT identity, as internal challenges to the fidelity of OT (Fischer, 2014; Ghul & Marsh, 2013; Wilding & Whiteford, 2007), and competing dominant discourses

externally ensue (Asbhy et al., 2015; Wilding & Whiteford, 2007). McCorquodale and Kinsella (2015) purport that striving for evidence-based practice may devalue our core goals of understanding meaning and narrative as central theoretical tenets. Prior to this, Mattingly and Fleming (1994) asserted that narrative could also be used to describe a type of reasoning employed by occupational therapists, as they used storytelling to rewrite and reimagine the client impacted by disability in managing meaningful life changes. However, this reasoning was often underrepresented both in general discussion and formal documentation, impacted by the conflicted practice of therapists, as they attempted to align biomedical and phenomenological underpinnings in interpretation of disability to promote successful intervention (Mattingly & Fleming, 1994).

Others assert that the compatibility of ICF with other pertinent theoretical concepts in OT must be researched, to solidify our professional role within multidisciplinary healthcare (Hemmingsson & Jonsson, 2005; Larson-Lund & Nyman, 2017). Despite debate, education in ICF as a critiqued conceptual model integrated into OT studies will equip students with the skills and knowledge to reason and compare theories, evolving global discourse on disability, function and rehabilitation (Pettersson et al., 2012). Further, in their review of a first year OT student programme, Ghul and Marsh (2013) purported that students may be more client centred, by using narratives and exploration of multiple paradigms from which to explore a person's sense of, and physical self within the societal context and concept of OJ.

2.10 Chapter Conclusion

On concluding this chapter, it is timely to review my research questions. Within earlier configurations occupation and participation were obscured by some

superfluous terms. For example, originally my first questions asked: "*How do people with enduring mental health disability experience participation when enacting occupation in their social environments?"* Within this, occupation was positioned less prominently than participation, instead of foregrounded as it is in the below Figure 1. Additionally, in the remaining two questions I had distinguished the social dimension of the environment, but on reviewing relevant literature this discounted the situated nature of occupation as well as the important cultural, institutional, and political environmental dimensions.

2.10.1 Figure 1: Final Research Questions

Final Research Questions:

1. How do people with self-reported mental health disability participate in or experience occupation in their local, familiar environments?
2. Do people with self-reported mental health disability express feelings of belonging to their community and other environments through enactment of occupation?
3. How do participants feel their environment has influenced their occupational possibilities?

The literature pertaining to participation, health and disability is vast and diverse. Within this chapter perspectives were considered by authors from within disability research, OS and OT in relation to specific conceptualisations of health, participation and occupation, and the operationalisation of these concepts within Irish and global policies. The centrality of the lived experiences of health and disability are paramount to all perspectives, offering insights into the complexity of participation in everyday life. For those navigating life with a mental health disability, the choices they expressed toward available occupations, within those contexts in which their lives were situated, was pivotal in their search for meaning, identity formation and in supporting their unique recovery processes. In the next chapter, I will outline my research methodology.

Chapter Three: Methodology

3.1 Chapter Introduction

The intended outcome of this research is to illustrate the participants experience of the forms and meaning of occupations within their communities. It is hoped that this will ultimately contribute to our understanding of the relationship of occupation to health, informing continued advancement in research and practice in this area. To gain this understanding a qualitive research framework was adopted. The suitability for qualitative enquiry in measuring the complex construct of occupation is well established (Clark et al., 1997; Yerxa, 1991) with additional innovative measures now proposed to evolve research and prompt greater understanding of the unspoken and unseen elements of doing (Huot & Laliberte Rudman, 2015; Lynch & Stanley, 2017). Yerxa (1991) compellingly explains the essentialism of qualitative research to OT in advancing its professional knowledge and upholding authentic, occupation-based practice. Despite this robust argument, qualitative inquiry in OS is challenged by access to funding and rejection on grounds of legitimacy (Clark, 1997), while foregoing qualitative methods in lieu of venerated gold standard research evidence, prominent within medical fields (Yerxa, 1991). However, Clark (1997) dispels this, noting its suitability in studying human occupation, within everchanging contexts:

> "..... *disciplines whose purpose is to increase our understanding of human activity, such as occupational science, need to use methods that can generate knowledge without disavowing the complexity and contextual variability of human behaviour*" (Clark et al., 1997, p. 314).

Reflecting this, I pursued a qualitative research framework, creating the opportunity for researcher involvement through facilitation of semi-structured interviews and observation. This involvement is important in the shared generation of meaning, acknowledging my impact in the interpretation of findings, described by Carpenter

and Suto (2008) as, *"researcher as research instrument"* (p. 29). In this chapter, I will outline my research framework and rationale for the methods chosen in order to answer the research questions as introduced in the first chapter of this thesis.

3.1.2 Evolution of this Study's Research Questions

On embarking on this research, I had afforded the construct of participation greater prominence within the research questions as detailed in Figure 2 below. However, compared to my final questions detailed in previous chapters, occupation was foregrounded over that of participation.

3.1.2.1 Figure 2: Original Research Questions

1. How do people with self-reported mental health disability experience participation when enacting occupation in their local, familiar environments?
2. Do people with self-reported mental health disability express feelings of belonging to their community and other environments through enactment of occupation?
3. How do participants feel their environment has influenced their occupational possibilities?

3.2 Research Framework and Rationale

In response to the above research questions, I adopted narrative enquiry to capture the stories of those with experience of mental health disability as they engaged with the phenomenon of occupation in their environments. Further, combining phenomenological and narrative perspectives guided my thinking, preserving the participant's stories while elucidating the shared meaning of occupation.

3.2.1 Underlying Phenomenological Perspective

As, Creswell and Poth (2018) outline, narrative presents stories, but phenomenology provides a framework from which to derive shared meaning of a global phenomenon experienced by many. Phenomenology is presented as an approach which could offer further insights into the discipline of OS, as it too attempts to move away from objective measurement of therapy and reflect utmost regard for understanding the experience of occupation (McLaughlin Gray, 1997; Park Lala & Kinsella, 2011; Yerxa, 1991). Finlay (1999) accredits the surge in interest within OT toward this approach to the influential research by Mattingly and Fleming (1994) describing occupational therapist's multifaceted clinical reasoning (Finlay, 1999). These researchers described the phenomenological anchor to occupational therapist's thinking and resultant interpretation of the meaning of their clients' actions (Finlay, 1999; Mattingly, 1991; Mattingly & Fleming, 1994).

Important theoretical assumptions within phenomenology dovetail with prominent constructs in OS, specifically the components of intentionality and the lifeworld articulated by the former. Viewed from this perspective, the lifeworld defines the physical structures and things within a person's environment, of which meaning is bestowed upon by the person's everyday actions (Park Lala & Kinsella, 2011). Additionally, a central aim of phenomenology is to understand the state of *"being",* and its meaning within everyday experiences (Reed et al., 2010; Park Lala & Kinsella, 2011). Like OS, this attaches significance to inextricability of humans and their environmental surrounds, with McLaughlin Gray (1997) directing our attention to the necessary parameters of meaning and environment in defining occupations. McLaughlin Gray (1997) points again to the dialogue within OS regarding the shifting definitions of occupation and offers phenomenology as a suitable method to clarify this construct. Phenomenology also fits with changing directions in the definition and categorisation of occupation to consider meaning, a concept which has seen limited research and definition within OS and OT (Hammell, 2004a; Reed et al., 2011). Choice, enactment and capacity for occupation may too be elucidated through a phenomenological perspective (Park Lala & Kinsella, 2011).

Emerging from Philosophy, phenomenology offers a perspective attached to specific theoretical underpinnings, foremost of which is a quest to return to the

generation of knowledge about individual experience, moving beyond a solely objective, scientific approach (McLaughlin Gray, 1997; Park Lala & Kinsella, 2011; Creswell & Poth, 2018). The application of phenomenology requires the researcher to embark on an approach to understanding which dispels biases and assumptions, to expose the essence of phenomena (Park Lala & Kinsella, 2011), This concept is referred to as *"transcendental reduction"* or *"bracketing"* (McLaughlin Gray, 1997; Park Lala & Kinsella, 2011). However, the applicability of this is questioned, with uncertainty about the researcher's ability to completely remove their personal interpretation or knowledge from the research (Park Lala & Kinsella, 2011; Creswell & Poth, 2018). Finlay (1999) summarises the aims of phenomenological methods to:

> *"..... Understand, describe and interpret human behaviour from the perspective of the person being studied"* (Finlay, 1999, p. 299).

This research study is concerned about what, why and how participants enact occupation in their familiar, local environments, specifically the personal meaning of this participation to them. Reed et al. (2010) ascertain that a combination of phenomenology and narrative can contribute to understanding meaning as it relates to occupation (Reed et al., 2010). Applying phenomenology, they describe the way in which it influenced their thinking, noting:

> "*Rather than a set process, the researcher engages with the text of the participants, and a process of inquiry emerges"* (Reed et al., 2010, p. 143).

Elaborating, they note that engaging in *"reading, thinking and writing"* encourages and integrates this reasoning into ideas. Through the collection of participant stories via narrative interviews the authors attempted to uphold the integrity of participant's own wording of accounts, sought participant review and continually engaged in re-reading to order these stories, employing phenomenological questioning to establish the meaning contained within them (Reed et al., 2010). A phenomenological methodology is appropriate in capturing the complexity of human

experience and intention when attempting person centred research concerning mental health (Borrell et al., 2014; Finlay, 1999; Sutton et al., 2012).

3.2.2 Adopting a Narrative Approach to Inquiry

The narrative theory underpinning this study guided the research design, methods and informed data analysis. Polkinghorne (1995) broadly describes the term narrative within qualitative research as any data taking the form of spoken word such as interview. Adding that use of the term "story" has become more current denoting the composition of related events enacted within a person's environment to produce complete and meaningful outcomes (Polkinghorne, 1995). Others have also described narrative as hearing and documenting stories that are situated within a person's context including their experiences, history and culture (Clark, 1993; Creswell & Poth, 2018; Mattingly & Lawlor, 2000). Polkinghorne (1995) further elaborated encompassing two distinct variations in the way that we think: paradigmatic and narrative cognitions which in turn inform narrative inquiry. The first deals with categorising concepts based on shared characteristics, with the second concerned with relating each human action to one shared purpose (Polkinghorne, 1995). Results from Mattingly and Lawlor's (2000) cross-cultural study of the healthcare experiences of minority families in the United States, determined the potency of narrative as a mechanism to publicise the silenced experiences of disempowered groups.

To fully understand the participants' experience of occupation in this study, it was vital that I capture their stories wholly and accurately. Narrative offers an integrated perspective of a person's experience of disability or illness (Clark et al., 1997; Mattingly, 1991; Mattingly & Fleming, 1994; Polkinghorne, 1996) highlighting the significance of personal stories in defining and redefining the self over time (Asaba & Jackson, 2011; Clark, 1993; Polkinghorne, 1995; Price-Lackey & Cashman, 1996; Whiteford, 2007). Like narrative, identity is considered within the context of time and place, moulded by changing interpretations and actions in response to circumstances (Christiansen, 1991; Clark, 1993; Isaksson et al., 2007; Polkinghorne, 1996). Polkinghorne (1996) draws on identity theory to explain humans as whole

beings wherein identity is considered a system filtering life experiences and intentions into a comprehensible outcome. He asserts narrative as the mode through which people can knit their actions into an organised plot, shaped over time by their goals, circumstance and experience (Polkinghorne, 1996). The link between identities and environments has been established by others, also employing narrative methodologies (Asaba & Jackson, 2011; Laliberte Rudman & Aldrich, 2017).

3.3 Research Methods

Combined interview and observation methods were chosen for this research to reflect the narrative and phenomenological perspectives underpinning my research framework. These methods and rationale for their use is described in this section.

3.3.1 Interview

Adoption of interview within qualitative research is the most frequently preferred method (Carpenter & Suto, 2008; Creswell & Poth, 2018). Narrative interviews were adopted to encourage storied accounts of participants' experiences (Asaba & Jackson, 2011; Mattingly & Lawlor, 2000; Polkinghorne, 1995), that is, when the interviewer refrains from imposing a restrictive interview protocol (Polkinghorne, 1995). Interview can be defined as: *"…. a social interaction based on conversation"* (Creswell & Poth, 2018, p. 163). Typically, interview has been considered as either structured or unstructured in its format however, Carpenter and Suto (2008), assert that the term "in-depth" is utilised to offer greater clarity in justification of the choice of method reflective of its qualitative theory. Further, flexibility in its organisation, purposefulness and access to personal interpretation of life circumstances are defining characteristics of qualitative interview (Carpenter & Suto, 2008). The intention to use open-ended questions within this research study, maintained fidelity to qualitative enquiry by using a method which seeks to explore the meaning and value of participant experiences (Carpenter & Suto, 2008). Organisation of the

interview in this way, provided subtle direction while allowing for the generation of plentiful data to answer the research questions. Prior to meeting participants, I piloted the interview protocol with a colleague to adequately prepare and adapt it to ensure it reliably answered the overarching research questions (Creswell & Poth, 2018). Interviews occurred in familiar environments chosen by the participants, were face to face and one to one with the researcher.

Consistent with phenomenological theory, questions pertaining to occupation did not include existing categories or theories of occupation (Reed et al., 2011) as researchers are obliged to exclude existing attitudes and maintain a somewhat neutral stance (Carpenter & Suto, 2008). Interviews began with a broad question enquiring about participant's recent experience of doing within their everyday environment (see Interview 1 Schedule in Appendix 6). I delved deeper into the significance of each participants' responses by asking probing questions, to:

> *"… Move from broad descriptions of situations to vivid and fine-grained stories of particular events"* (Mattingly & Lawlor, 2002, p. 9).

Refined questioning was used as the interviews progressed to create an illustrious and flowing story whereby the researcher can focus intently on listening significant passages of the participants' narrative (Mattingly & Lawlor, 2000). In the second interviews, questions were formulated based on the stories heard in the first interview, supplemented by observations, with each participant's second interview schedule adapted in response (Appendix 7). This was also an opportunity to clarify content, my interpretations and build on discussion from interview one.

3.3.2 Observation

To facilitate a more accurate and meaningful exchange of experience across cultures, for example researcher to participant, Mattingly (2000) advises that narrative be supplemented with observation to produce valid results. Further, meaning cannot be understood with observation alone, without also listening to the person's experience of occupation (Reed et al., 2011). The researcher in this study was a *"complete*

participant" during observation, defined by Creswell and Poth (2018) as: *"… Fully engaged with the people he or she is observing"* (p.167).

For example, Spitzer (2003) justified her rationale for using qualitative measures, specifically observation to measure meaning of occupation for young children with developmental disabilities. The author adopted the term "occupation-mediated" describing the process of obtaining information through observing a child's actions or intentions (Spitzer, 2003). She described the subjective nature of meaning and with this perspective, the need to apply interpretation in order to contribute to our knowledge base of this construct (Spitzer, 2003). The researcher's ability to become immersed in the occupation, using interaction to confirm or alter interpretations as needed, can support greater validity of this method (Spitzer 2003). Lynch and Stanley (2017) also adopted observation in their study with children to determine the transactional components of their occupations. The researchers were participant observers offering an empowering method of: *"… Gaining insight into the participants occupational world"* (Lynch & Stanley, 2017, p. 9). The observation studies described demonstrate the necessity of field notes to translate action into word (Lynch & Stanley, 2017; Spitzer, 2003).

3.4 Recruitment and Sample Description

3.4.1 Recruitment Design Plan

Qualitative research is concerned with extremely detailed individual accounts, and less concerned by the quantitative goal of generalisation and other positivistic methods (Carpenter & Suto, 2008; Creswell & Poth, 2018). By choosing participants with a self-determined mental health disability, highly specific participant information imbued with cultural and personal meaning was obtained. This supported the underlying phenomenological framework of learning about this phenomenon from people who have experienced it (Creswell & Poth, 2018). Purposive sampling was used to recruit a maximum of three participants who

identified as having a self-reported/self-determined mental health disability. For the purpose of this study purposive sampling is defined as:

> *"…. deliberately selecting particular settings, person or events for the important information they can provide that cannot be acquired as effectively through other means"* (Carpenter & Suto, 2008, p.78).

Purposive sampling was used to recruit participants via self-selection following advertisement within Irish mental health support networks. I emailed the research flyer (Appendix 2) to two local organisation and two national mental health support networks.

3.4.2 Recruitment

The recruitment phase of this research occurred from March 2019 to May 2019. Of the mental health support organisations and networks contacted one network declined and the other accepted. Two local organisations did not return correspondence despite follow up. I spoke directly with a Coordinator within the mental health support network who agreed to participate, who in turn sought three participants in a single Irish province. Participants were informed about this study through a research flyer (Appendix 2), circulated by the mental health support network coordinator. Prior to using this flyer, I reviewed it against the Health Service Executive "Guidelines for Communicating Clearly using Plain English with our Patients and Service Users" (2018) and tested it with lay people to ensure the content was clear and understandable. The coordinator provided me the contacts of participants who self-selected to be part of the study, whom I then contacted individually by email and by phone to discuss the study and summarise the information leaflet (Appendix 3), including its purpose and research aims. Participants agreed to meet with me, in a venue of their choice within their local community, to discuss the information leaflet. During this discussion, I obtained their informed consent (see Consent Form, Appendix 4).

3.4.2.1 Table 1: Participant Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
• Capacity to consent • Over the age of 18 • Identify as someone with a self-reported Mental Health Disability	• No self-reported mental health disability

Three adults participated in this study, two men and one woman: Jane, Dave and Tim[4]. They each participated in two interviews and one observation with me. I met with Jane and Tim on two occasions and Dave on three occasions. All participants were Irish, had a formal mental health diagnosis and were continuing to access community based mental health services. More detailed accounts of their backgrounds are provided in the findings chapter.

3.5 Data Collection

A maximum of three participants were recruited to allow for the collection of in-depth and rich data about the meaning of their experiences. Interview and observation methods were adopted in keeping with the phenomenological and narrative theoretical framework underpinning the research. The data from this research was gathered collaboratively with participants' through interview and observation methods over a period of two months in 2019. All participants chose to pursue their interview one (Appendix 6) directly after providing their informed consent. First, participants were interviewed by the researcher to explore their perspective of their experience within their environments, when enacting occupation in everyday life. Each participant and researcher then pursued

[4] Jane, Dave and Tim are pseudonyms used to protect participant confidentiality.

meaningful co-occupation in the participant's local, familiar environment, with the researcher as a fully active participant. Through this participation observation was used to supplement the narrative obtained. Finally, a second interview (Appendix 7) with each participant gathered their reflections of this specific experience of co-occupation with the researcher in their chosen environment. Data collection is summarised in the table below.

3.5.1 Table 2: Summary of Data Collection:

Participant	***Interview 1***	***Observation***	***Interview 2***	***Field Notes***
Jane	Date:03/05/2019 Transcript Pages: 39	Date: 28/05/2019	Date: 28/05/2019 Transcript Pages: 36	Pages: 6
Dave	Date: 20/05/2019 Transcript Pages: 45	Date: 10/06/2019	Date: 18/06/19 Transcript Pages: 49	Pages: 7
Tim	Date: 28/05/2019 Transcript Pages: 44	Date: 26/06/2019	Date: 26/06/2019 Transcript Pages: 33	Pages: 3

3.6 Ethics and Study Rigour

Ethical approval was granted by University College Cork (UCC) in December 2018 (Appendix 1). Garda clearance was approved by UCC as the categorisation of participants "as vulnerable adults" under the Irish The National Vetting Bureau (Children and Vulnerable Persons) Acts 2012 to 2016. Potential power imbalance is an ethical issue I anticipated as participants may have felt obliged to respond affirmatively or comply with requests, in reaction to the researcher as a perceived expert. To distance myself from this I recruited participants external to my clinical work. As detailed by Creswell and Poth (2018) interviews can be challenged by the interviewer-interviewee relationship such as unequal status when one person is

seeking information and the other provides it. Collaborative exchanges and reflection are highlighted as strategies to combat this (Creswell & Poth, 2018) and were adopted by this researcher. To minimise interviewer bias, I relistened to audio recordings, maintained a reflective journal and engaged in frequent reviews with my supervisors to critically examine my interpretations and analysis. This was further redressed by assuring participants of their personal expertise in sharing their experience, from their point of view, assisting my understanding.

Interviews and observations were conducted in familiar environments, chosen by participants to promote autonomy and reduce any imbalances which could occur within a contrived environment. As the interviews were open ended and this research was overall collaborative in nature, this may have further corrected any power imbalances by encouraging equal contributions and interpretations by both the researcher and participant (Creswell & Poth, 2018). Spitzer (2003) promoted use of observation as a qualitative method which could decrease researcher-participant power imbalances by offering greater exposure and clarity to the participant's intended actions, indicating more likely determinants of meaning. Additionally, Lynch and Stanley (2017) described facilitating their research within the children's home environments, with observation protecting their rights and agency, offering increased choice and expression, and an alternative to narrative alone (Lynch & Stanley, 2017). Considering how the rights of adults with mental health disability have been denied (Hamer et al., 2014; Townsend, 2012), observation offered a method for this researcher to protect their rights and offered more flexible options of participation.

3.7 Data Analysis

Interviews were recorded digitally and transcribed verbatim by the researcher. Each interview lasted between 50 and 90 minutes. As described by Bailey and Jackson (2003) I transcribed the interviews verbatim to ensure proximity to, and increased

knowledge of the data. Field notes were utilised by this researcher immediately after each participant interaction to promote recall and accuracy of data collection. Data collected using field notes included descriptions of the place, time, people, occupations chosen, and actions, these amongst others are typical of this process (Carpenter & Suto, 2008; Creswell & Poth, 2018). All data was anonymised, and any further identifiable information removed, while still providing rich participant accounts. Dickie (2003) describes qualitative data analysis as a process through which OT can distance itself from an over reliance on quantitative descriptions of methods and results. She emphasises each researcher's responsibility to clarify their analytic journeys as they make inferences about findings (Dickie 2003).

Thematic analysis was adopted in this study. Citing, Braun and Clark (2006), Carpenter and Suto (2008) define this as: *"… A method for identifying, analyzing and reporting patterns (themes) within the data"* (p.113-114). Carpenter and Suto (2008), offer guidelines to qualitative data analysis, occurring over three stages. However, noting this is not a formalised protocol, cautioning that this approach must be flexible in responding to the research questions and their underlying theoretical framework (Carpenter & Suto, 2008). These guidelines were adopted to manage and analyse the data collected. Firstly, "data reduction":

> *"… Involves the researcher selecting, simplifying, abstracting and transforming the data that appear in written up field notes or transcripts"* (Carpenter & Suto, 2008, p. 114).

I undertook this by coding each interview transcript, inserting comments in the margin, reviewing, and compiling this data with my field notes and reflections. Data obtained from field provided further triangulation of data offering context to the location of occupations and situating participant narratives. Secondly, "data display" requires diagrammatic representation of data to support the researcher in observing emerging patterns as the data is grouped in similar chunks carefully avoiding premature determinations (Carpenter & Suto, 2008). In this stage I isolated the codes from each interview in a separate document, printing and cutting out each code. I grouped these codes into themes and organised them into a table (see Findings

chapter). According to Carpenter and Suto (2008) gradually building a more interpretive analysis, arriving at the "data reduction" stage requires detailed reading of the different layers of meaning contained within the data. Simultaneously ensuring critical peer review and researcher reflexivity, promoting credible conclusions (Carpenter & Suto, 2008). Once, I had organised the themes I set about drafting my findings chapter. Prior to this however, I presented a poster (Appendix 5) to the Occupational Science Europe Conference in August 2019, presenting my emerging data as displayed in the below graphic.

3.7.1 Graphic 1: Emerging Data Themes



3.8 Evaluation of this Research

Within the methodology chapter, I outlined my rationale for a qualitative research framework. However, now, evaluating the quality of this research study, I return once again to Yerxa (1991) who asserted that accessing methods which reflect the theoretical origins of OT ensures more accurate knowledge generation,

substantiating the intended outcomes of enhancing health through occupation (Yerxa, 1991). She cautions, that should a reductionist approach be adopted to understanding humans as occupational beings, we would compromise our ethics by ignoring their experience of doing within their familiar environments (Yerxa, 1991). Carpenter and Suto (2008) assert that ethical and valid qualitative research must undertake to establish its trustworthiness or integrity. One such criterion discussed, citing Lincoln and Guba (1995) is that of dependability, whereby the researcher accounts for how research findings reflect the methods chosen (Carpenter & Suto, 2008). As outlined previously, this research was underpinned by phenomenology, along with a narrative focus, influencing method selection and data analysis.

The focus of this research has been to understand the participants' experience of occupation, including its form and meaning, this is evident in the use of their direct quotes throughout, amplifying their voices, consistent with other phenomenological (Blank et al., 2015; Reed et al., 2010; Sutton et al., 2012) and narrative (Asaba & Jackson, 2011; Mattingly & Lawlor, 2000; Sakiyama et al., 2010) studies. Additionally, Carpenter and Suto (2008) note the importance of quotes in supporting readers to judge the accuracy of the researcher's interpretation of the findings, while also highlighting the requirement to justify the inclusion of some quotes and not others. Blank, Finlay and Prior (2016) identified how verbatim participant quotes coupled with the questions adopted in interview contributed to transparency. I have included excerpts from the participants narratives abundantly within the text of this thesis to retain coherency of their individual stories, while generating shared themes. Repeated reading of these texts with an enhanced awareness of the participants environments through observation supported me identifying and analysing significant events within their stories.

Creswell and Poth (2018) in their discussion of research validation recommend that qualitative researchers adopt at least two validation strategies to evaluate the accuracy of the findings, from the perspectives of researchers, participants and peers. The validation strategies adopted in this study are summarised herein.

3.8.1 Reflexivity and Triangulation

Reflexivity centralises the researcher within the research process, necessitating disclosure of their position and background to it, upholding its integrity (Carpenter & Suto, 2008). I added to the study's trustworthiness through constant reflection, identifying my reasoning and integrating learning throughout by using regular supervision, post-graduate review meetings, field notes and a reflective journal. I stated any biases and experiences at the study start so that my perspectives were visible, contributing to overall transparency. Finding myself immersed in data analysis I relied on constant reflection to understand my own positioning within the participants' narratives. In the process of data analysis articulated by Dickie (2003) some peaks in the process are apparent including recording, immersing and distancing herself from the data and segmenting or chunking data (Dickie, 2003). However, a further step is paramount as Dickie (2003) describes her transition from "sorting" to the "interpretation" of the data in relation to her research and theoretical stance. She stresses the significance of full transparency in the interpretation of findings (Dickie, 2003), a belief consistent in the method of analysis outlined by Carpenter and Suto (2008). I interpreted findings through listening to recordings multiple times during transcription and capturing my thought process within my reflective journal. I coded each participant excerpt within their completed narratives, then separated these codes, to compile them into a *"thematic whole"* (Sutton et al., 2012). Further, checking and re-checking data against the research questions in collaboration with my supervisors, editing accordingly to promote proximity and consistency to the process overall. On reaching a more complete version of my findings chapter, with analysis and feedback from my supervisors, I found myself needing to revisit existing literature to connect the data with theory (Carpenter & Suto, 2008; Dickie, 2003). Finally, coinciding revision of my findings and discussion chapters, I reflected on my decision making and interpretation, while returning to prominent theorists to elucidate constructs and consolidate my thoughts.

Collecting data from both observation and participant narratives, indicates triangulation whereby more than one source is adopted enhancing a study's

credibility (Carpenter & Suto, 2008; Creswell & Poth, 2018). In this study, data was sourced primarily from analysis of interviews, with observations communicating in-depth meaning of occupation and context, substantiating interpretation (Lynch & Stanley, 2017; Spitzer, 2003). Field notes completed after each interaction enhanced accuracy and recall.

3.8.2 Participant Involvement and Peer Review

This sample size allowed for the collection of in-depth and rich data from participant's stories, elucidating their experience of occupation in keeping with the phenomenological and narrative theoretical framework (Creswell & Poth, 2018) underpinning this research methodology. Prior to the observation and second interviews with each participant I transcribed their first interviews, adapting questions in the second interview schedule referring to the previous interview content. This provided an opportunity to check my preliminary interpretations and delve deeper into topics. The participants and I collaborated in choosing the interview venues and constructing the observations. The participants had increased time to reflect on their choice of observation which we primarily organised over the phone, between interviews. Tim and I discussed at the end of his second interview his interest in getting to see the completed research. He declined to view his transcripts but considered involvement in some forum where the research findings could be disseminated amongst their mental health support organisation, Dave too considered this.

In their discussion of trustworthiness, Reed and colleagues (2010) ascribed how consulting scholars and clinicians regarding emerging findings, ensured their research was "*understandable and appreciable"* (p. 143). The evolving findings from this study were presented at the Occupational Science Europe Conference during which I had the opportunity for peer review, furthering my reflection and discussion amongst OS scholars.

3.9 Chapter Conclusion

The adoption of narrative and observation within this study, offered research methods capable of authentically rendering the personal experiences of occupation as authored by the participants and situated within their unique cultural contexts. The current study may contribute to the growing research within OS attempting to understand the phenomenon of occupation by generating increased knowledge about the forms of occupations chosen by people with mental health disability and subsequently how these create meaning, shaping identities and lives. In the following chapter, I will explore and present my analysis of this study's findings as elucidated through participant excerpts.

Chapter Four: Findings

4.1 Chapter Introduction

This chapter presents the primary themes and subthemes gleaned from the six participant interviews and three observations. The participant's stories are discussed both separately and together to offer the reader an opportunity to consider both collective experience while preserving the integrity of individual narratives. Their experiences navigating occupation within their community spaces and amongst significant others is described, and reflected upon, herein.



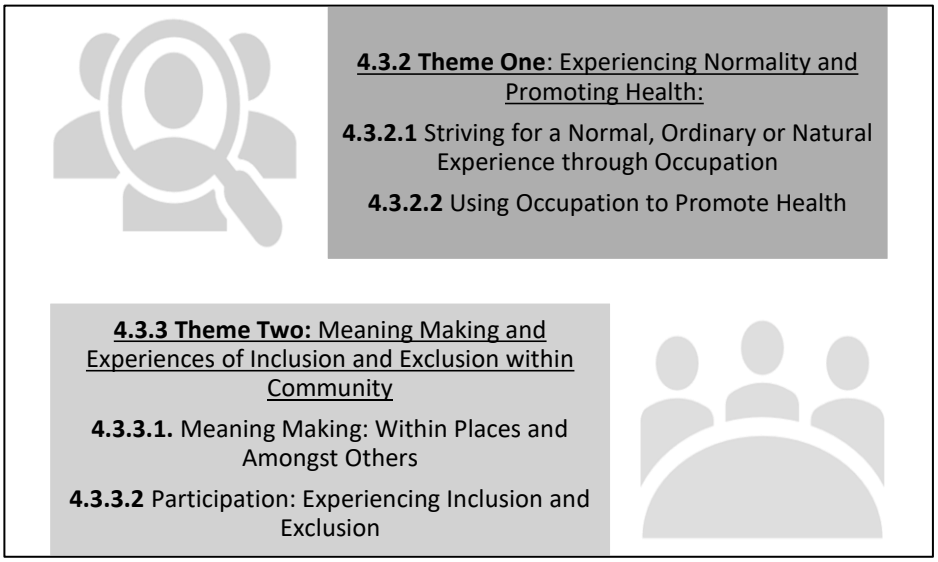


Cassidy, C. 2020. Occupation, identity and belonging within community: experiences of mental health disability. MRes Thesis, University College Cork

Please note that Section 4.2 (pp.75-77) is unavailable due to a request by the author.

CORA Cork Open Research Archive http://cora.ucc.ie

4.3.1 Graphic 2: Themes Summary



4.3.2 Theme One: Experiencing Normality and Promoting Health

Each participant described experiences of feeling or anticipating feeling normal through their participation in occupation. The words normal, ordinary and natural were employed to convey participant's use of occupation as a conduit for a *"normal"* life experience acceptable to themselves and to others. Quests to feel normal or obtain a prosaic lifestyle appeared driven by the participant's personal values while also imbued by familial, community and societal expectations. Within this theme two subthemes emerged: *"Experiencing Normality through Occupation"* and *"Using Occupation to Promote Health"*, these are presented herein.

4.3.2.1 Striving for a Normal, Ordinary or Natural Experience through Occupation

Participation in occupation was described as a conduit for experiencing or hoping to experience a sense of normality. This appeared particularly evident within the occupation of work. All participants referred to work, whether paid, unpaid, full time, part-time or voluntary as a means through which to experience normality. For example, in relation to her long-held desire for work, Jane commented:

"I had wanted to work, like it's a normal thing, nearly everybody can earn their living and it's the right thing to do when you're involved in society. You have a routine and you have an income..."

Jane articulates both the personal and societal expectation to contribute to society affording a highly valued identity as a responsible member. Words such as normal and ordinary tended to reappear in Jane's narrative particularly in the meaning she found through work. Reflecting on her current worker identity she expanded:

"… And I'm a worker and I'm contributing to society. You know I found that very hard. Apart from any financial benefits, I found it very hard not having (pause) any meaningful interaction with, I kind of was just, living at home and doing nothing sort of way, and I didn't like it and you know, I felt it wasn't mature, and it wasn't responsible or it wasn't normal and it's not what most people do…"

Jane's identity is intertwined with being both employed and unemployed. When she was unemployed, she illustrates her profound loss of social and financial benefits, distinguishing herself as abnormal or irresponsible. Tim too emphasises the value he bestows on paid work and its meaning to his worker identity:

"... When I'm in the (name of mental health community) I feel like I'm kind of working I feel like I'm actually working which I really value. I really, like I used to work, I worked in bars and restaurants for a long time … I was probably 16 when I started working and I worked, worked and worked and worked."

Preparing for paid employment through work-based tasks at his mental health community meant Tim felt as if he was working, strongly reflecting his values, reigniting his worker identity. Conversely, his perception of being unemployed diminished the value of other occupations as described in this excerpt:

"... I did a meditation course with them and I kind of would like to get back to it but I, my schedule is kind of not allowing it at the moment you know, just, I know (laughs) what kind of a schedule with someone who hasn't a job, you know what I mean, ..."

Tim appeared to value paid employment above other occupations, eclipsing efforts he was making to improve other aspects of his health, possibly perpetuating feelings of abnormality and marginalisation. This was somewhat shared by Dave in his reflection on the value he attached to paid employment:

"There probably still is stigma around schizophrenia alright. But with all this help in the community. And with all the friends that I've made through (name of mental health support organisation) it's, it's great and I've my sister and that. But I'm still, probably not, because I'm not doing a proper job, over the years I've just had, I've had some work, like part-time work and CE schemes and whatever, voluntary work, so, I've never been in mainstream work."

Dave clearly values his social supports and views the increased opportunities for mental health support in his community as signs of stigma reduction. While recognising too his past work efforts, his restricted experience of full-time paid work separates him from others.

Experiences of perceived normality were not limited to paid employment. Meaningful creative occupations such as art, craft and music were sought by participants. Creative occupations, often pursued with others, offered enjoyment, connectivity with their social worlds, security and acceptance. For example, Dave, reflected on a local art class within his peer led mental health group:

"... one of the chaps is quite quiet, he'd hardly say a word, eh, but, that's ok in an art group, it's less awkward or, it's more natural."

Through the occupation of art, the focus was on doing, offering a sense of security, where a quieter attitude was unidentifiable as social difference. Tim highly valued his occupation of playing music both alone and with others. Like Jane earlier, he shared a conviction of using occupation to do the right thing, as portrayed in his description of his live musical performance:

> *"… sometimes I can get quite anxious and maybe not feel that great, you know and think, awh, I don't want to do this, you know. But I've been trying to make myself push through and do things. And I know it's the right thing to do."*

For Tim, his perseverance with his musical performance, despite his anxiety, afforded him the opportunity to realise his identity as a musician while maintaining his friendship and sense of belonging with his fellow musicians by being reliable. Jane too shared a love of live music as a spectator. Discussing her passion for going to concerts in a small group, she commented:

> *"Well, I think it's great to get out for a night. And I enjoy the music, you know and the singing, take your mind off things and its good entertainment and you're with people you love, and other people do it. It's normal yeah, I like normal. I like, I like, normal too about work. You know I think that's very reassuring when you've had a troubled life and your mental health isn't too good."*

In the enjoyment and connectivity within this shared occupation Jane felt loved and part of her group, leading to reassurance and an experience of perceived normalcy. Overall, the participants narratives encapsulate the meaning of shared creative occupations in expressing a perceived normal identity, through feelings of belonging, enjoyment, connectivity and recognition through creative outputs.

4.3.2.2 Using Occupation to Promote Health

As the participants encountered disruptions to their daily lives due to disability or sought to master new health promoting habits and routines, they detailed their choosing and using of occupation to navigate these changes. The participants described choosing occupations that would promote their physical and mental health. For example, Dave chose to use more restorative occupations during periods when his energy was low to manage his mental health disability:

> *"… I think it's partly to do with the medication, I think it could be partly to do maybe with the psychiatric, maybe it's something more but my energy wouldn't be the best... I kind of get tired during the day, here and there you know. And then there would be once every two months for about two weeks, my energy does crash a lot and I feel kind of shaky, kind of my strength goes with that. So, for that two or three weeks I have to be very careful not to overdo it. Not to over rush, I find rushing, eh, can exhaust me when I'm in that kind of place…"*

By employing pacing to his daily routine Dave reflected how he regulates his energy and maintains his health. Adding his use of "check lists" help build momentum to access other health promoting occupations:

> *"... I might make a list of a few things I want to do the next day. And that helps me get around to doing them, you know so... you tick a few things off your list, you start feeling very productive and more motivated, you're more inclined to get the rest of the things on the list done."*

Jane too chose occupations to promote her health. Experiencing pain through repetitive physical tasks she chose to delegate more arduous domestic chores to her brother:

> *"... He really maintains the house eh. He does, I hate the hoovering. I have an (orthopaedic disability) so physical activity I'm not great at."*

Through exercising this choice Jane protected herself while choosing alternative occupations reflecting her carer role with her parents and family. Using TV to relax and accessing enough sleep were important to Tim's night-time routine in managing his health:

> *"... Maybe watch a little bit of telly... just to relax you know. Eh and then try to head to bed reasonably early, try not to stay up too late or anything…"*

Tim reflected on the need to access occupations which were relaxing, supporting him in sleeping well, promoting his health. Dave described the impact of his mental health disability on his energy and arousal levels choosing to alter his eating habits to change this:

> *"... I've cut out dairy, sugar, wheat. Now I feel a little bit brighter in myself, on the medication you're a bit dulled, but I feel a bit brighter.*

Altering his diet was a significant change Dave made to feel more energised and alert. Jane too spoke about the need to manage her diet:

> *"… Now, I'm more balanced, I have lost nine pounds since em, you see with the orthopaedic disability if I put up too much weight in my tummy, it could kill me."*

Jane's management of her diet was essential to promoting both her mental health and physical health.

Additionally, all participants chose meditation as a restorative occupation to promote or protect health. For example, Jane referred to advice she received from a friend:

> *"… And she says, 'keep the head, you're no use to yourself or anyone else if you lose the head', so, meditation could be a, a help to me in that."*

Jane expected that meditation could be useful in supporting her to manage her mental health by keeping herself and her thoughts calm, supplementing frequent attendance at quiet prayer meditation in her local church. Whereas Dave had been actively using meditation to manage his health for some time:

> *"I, I practice mediation twice a day as well... And then I try to put mindfulness into practice during the rest of the day. Just to kind of wake up realise when you're in your head, thinking or worrying or fretting or self-preoccupied ..."*

For Dave, meditation served as an occupation which could transform his day to day life by identifying and altering his mood. Like Dave, Tim included meditation as part of his daily routine:

> *"... I sometimes listen to kind of eh, spiritual recordings on, on the computer just to get me in the head, head space for the meditation and then I do maybe a half hour meditation."*

Meditation played an important part of Tim's morning in preparing him for the day ahead by getting into a calm "head space". Thus, the restorative occupation of meditation was meaningful to all participants in looking after themselves and their relationships with others.

Further, all participants made attempts to protect or enhance personal health through seeking out occupations to do with others. They often sampled new community experiences through co-occupation. This collaborative experience through occupation created a sense of being in and belonging to their communities. This encompassed varying quantities of accessing peer support, health services and spending time with friends and family. For example, each participant was a member of at least one peer led group that they attended as part of their weekly routines. Illustrating this, Tim actively attended his local mental health support group and noted personal goals he pursued as part of his weekly attendance. He discussed making plans to return to spectating at sports events:

"So, I did that, and went to a match and really enjoyed it you know. So, its, it, kind of helps you get out and do things like you know."

Tim received encouragement and problem solving from his peers to access this valued occupation, reflecting his longstanding interest in sport. This achievement was part of his mental health recovery. Similarly, the health promoting benefits of Dave's group membership are clear in the following statements:

"To get to my (name of mental health support organisation) meeting, very good. It could actually swing it and make me feel a lot better."

Dave reflected on his group's impact in transforming his day through the understanding and support of his peers. Like Dave, Jane detailed her history with her mental health support group and her resultant employment with the organisation:

"Now, I don't know what other mental health organisations are like for people with a fairly serious mental illness. But, mine has been a God send."

For Jane her participation and experience of this group has been life altering. Thus, peer support groups were significant occupations in the lives of the participants in experiencing belonging in their environments. Additionally, Dave and Jane described regular beneficial contact with their mental health services. Dave noted that:

"… I have, actually a Consultant and a registrar to ring as well. I find if I am a bit low that way or a bit psychotic that way it is good for me to get in touch with people."

As well as friends and family, Dave included his psychiatrist and registrar amongst his contacts to connect with and support him in managing his mental health. Jane remembered how she protected her health by compelling her Psychiatrist to discontinue a prescribed injection:

"... I said to them, you know, take me off this injection, I am working five days a week and life is normal and things are ok at home and after a few months they said alright"

Jane used her participation in occupation as an example of health so that she could emphasise and evidence her wellbeing, while actualising her right to be included in her care planning. Generally, choosing occupations with others was determined by participants to be health promoting. Participants recognised the need for some contact with others and exercised their choice of the amount needed. Dave illustrates this in the following:

"... Over the years I've found that it's good for me to have some social contact during the week or even once a day. I find if I meet somebody even for an hour or two, or with a group for an hour or two that's good for me now..."

Dave also reflected on feeling pain around not having a career or family like his peers. He shared his perspective around forming romantic relationships, considering this as a possibility:

"... the last few years, I, I literally would have been too unwell now, and it just wasn't on the horizon at all. Now it's a possibility but it would have to be with somebody else, that would also have psychiatric, otherwise it would just be too different."

Like Dave, Tim reflected on his need for varied connection with others. Now, he felt it was good for his mental health to enact occupations with others, contrasting with his previous preferences:

"I used to play PlayStation a good bit when I'd get up in the morning and I'm not proud of that like, but, I suppose I didn't feel well enough, you know, I felt a bit low in myself and so, now I feel a bit, a bit more able for life. And I feel like, I get a lot from connecting with people and, and having these occupations where I'm connecting with people…"

Tim illustrates his need to choose a simple, restorative occupation without others and the shame he felt, despite its health protecting benefits. He contrasted this against his current perspective, feeling more able for life and benefiting from connecting with others through varied occupations. Similarly, others' perceptions of normality influenced Jane's occupational choices. For example, reflecting on returning to her women's group, which she had discontinued following a close friend's passing, she described how her psychiatrist prompted her to return:

> *Jane: "So, I missed her. But the psychiatrist got onto me about two years ago and said you're spending too much time with elderly parents. So, I went back, although she's not there now."*
> *Researcher: Sorry to interrupt there, how did you feel been, been told that?* [5]
> *Jane: "Yeah I got on ok because I find the activity which I enjoy kind of carries you through you know you don't necessarily have to spend a lot of time in small chatter, getting into one to one… it's relaxed and it's pleasant."*

Choosing not to attend the group during mourning may have supported her in promoting her health. Alternatively, returning to the group, Jane was able to take solace through a relaxing occupation in a supportive environment.

This subsection has illustrated how Tim, Dave and Jane expressed their right to choose their occupations, adjusting their routines, selecting restorative occupations and determining how much time to spend with others to promote their health. Further, they all reflected on the meaning of their mental health support groups in accessing support, recognition and belonging.

[5] By enquiring further, I wanted to hear more, I thought Jane might say she felt like she was being told what to do by her Psychiatrist, demonstrating the dominance of the medical model. However, by Jane's response this was not how she felt. She reported she got on ok because she enjoyed the activity. Reflecting, I think this anecdote highlights the hidden complexity of service and service user relationships.

4.3.3 Theme Two: Meaning Making and Experiences of Inclusion and Exclusion within Community

This second theme is dedicated to exploring Tim, Jane and Dave's interactions with others as they pursued meaning making through occupation in their local environments, within places and amongst others. The first subtheme presents participant's descriptions of making meaning within frequented spaces and amongst others, with observations contextualising this discussion. Secondly, I will explore how participants experienced the duality of being part of their identified communities while also being separate or different from others, revealing experiences of both inclusion and exclusion. Within this second theme, stigma emerged across narratives from the participants and their surrounding environments, impacting feelings of belonging.

4.3.3.1. Meaning Making: Within Places and Amongst Others

Objects, buildings and spaces were important in how participants created meaning within their contexts. For example, Tim, detailed the impact of scenery and landmarks during his seaside walking route in creating a sense of home:

> *"… Because there's wildlife and there's people around and the sea is there, and we can see up (name of picturesque area) and stuff, so it just gives me a good feeling you know. It gives me a feeling like I'm, I'm comfortable and I feel at home, kind of, you know, where I am."*

It was meaningful to Tim to live in this picturesque area, benefiting his sense of wellbeing, while creating comfort and belonging. Tim's community encompassed neighbouring towns, villages and a city centre:

> *"... So, I like that you know, not to be too focused on the one place, like you know, I like to have a broader kind of horizon... I kind of like to have connections with things outside of, just a small local place you know."*

He reflected on creating meaning within additional community spaces and amongst others through the experience of occupation. Contrasting with Tim's description, Jane mapped her community by identifying her three most important and frequented environments:

> *"... I suppose here is community through work, and (name of home community) is community through living. (Name of University) was community through college."*

Significantly, Jane defined her environments through the meaningful occupations she enacted within them. Highlighting the role of objects in creating meaning, Jane, described her favourite pew within her local church:

> *"... It has a different shape at the end of it, compared to all the others, and when I'm coming back from holy communion... you come up the middle aisle and they're all these, I said now, where am I going, and I find my different shape at the end and I know where I'm going."*

While being essential for physical support, this pew was paramount for Jane in navigating the church amongst others, experiencing a sense of grounding and belonging by using it as an indicator. Objects too created meaning for Dave within his community:

> *"... I have a tree that I like to sit under, so, sometimes I sit under that tree, sometimes trying to get away from everything."*

This tree for Dave, was a familiar space within a larger environment offering an easily accessible sense of calm. Dave described the meaning he attached to being in nature:

> *"... Connecting with people, places, and just nature as well like you know... I find that connection, when I'm in a place where obviously I feel belonging*

with the people or a place where I'm on my own I can feel very peaceful. So, I suppose there's a big spiritual dimension there."

Dave reflected on the impact of people, places and nature on creating calm and peacefulness, making spiritual experiences a possibility. Thus, spaces and objects were significant in creating meaning for participants and possibilities for being and belonging within their communities.

Jane, Tim and Dave experienced a sense of belonging within their local mental health support groups. For instance, Dave described the meaning created when he returned to his local group:

"And then, when I went along for some reason I just stayed. I've always felt, at least the second time when I came, I got a sense of belonging, support, community, friendship."

Experiencing a strong sense of belonging and community in his group through finding others with similar life experiences meant Dave continued attending and developed lasting friendships. Like Dave, Jane noted the role of friends in creating meaning through work within her mental health support organisation after a period of unemployment:

"... And It was very good for me the routine, and getting out of the house, the daily routine and meaningful occupation is very helpful. But I'm very nervous and I'm frightened of people with the paranoid schizophrenia so, the ladies were a great help to me… And they socialised a lot with me you know."

Unlike Dave and Jane, Tim had been attending his group for a shorter time, but had no less meaning attached:

"… And I came for a couple of years … I got a huge benefit from it like, I got huge em, you know, freedom and, and help and support..."

Tim experienced a sense of freedom from finding others who validated his experiences and supported him in his recovery journey. He described increased visibility in the world through doing, specifically, becoming a more vocal and established member, adopting an enhanced leadership role within his mental health support organisation:

> *"… And it's amazing that more and more things, more opportunities for, for occupations become, em, available to me, the more I get out there like, the more I kind of become visible in life…"*

Tim's participation in occupation, highlights the poignancy of his occupational choice in showcasing his capability, largely driven by his longstanding value to contribute and "give back" to others.

Reflecting on this subsection, the physical objects and spaces the participants interacted with, alongside significant others in their lives, created meaning as they navigated their community environments. Feelings of belonging emerged from this meaningful participation, sustaining doing, while creating possibilities for new occupations and becoming.

4.3.3.2 Participation: Experiencing Inclusion and Exclusion

Experiences of enacting occupation were not easily defined as either beneficial or detrimental by participants. Collaborating with others through occupation was highlighted as needed and meaningful by all participants to support inclusion and belonging. Conflicting and sometimes simultaneous experiences of inclusion and exclusion were recounted, prevalent within past secondary and third level education environments. Most commonly, stigma or being treated differently, created experiences of exclusion coupled with participants' internal distress at feeling separate or marginalised.

As previously noted, meaning was created by being with others. However, this could generate both experiences of inclusion and exclusion

primarily generated during interactions with others that did not involve a meaningful occupation. For example, Jane reflected on her feelings about other people:

> *"... I care deeply about people in one way. And in another way, I'm frightened of them."*

As Jane was preparing to spend more time in her home community, she reflected on relying on significant others to feel included by developing links and feeling part of it:

> *"You know and their contacts and their knowledge of people and community, broadens me out and calms me down and gives me links you know that are normal, you know, more of a sense of community."*

Co-occupation held significant meaning for her in supporting her to venture into her community and feel a sense of belonging. Jane also acknowledged her own responsibilities in advancing inclusion:

> *"... I think it's my making strange, em, and a bad habit of starting things and not keeping them up. I think that's a bad habit, I think that's me."*

Jane noted her own role and that of others in supporting her to persevere with valued occupations and creating community. Further, she emphasised the meaning in her current worker role in establishing community:

> *"Em I think the community dimension in my job em, is very helpful to me and in other places where I wasn't successful in staying it was because ... the jobs hadn't so much meaning and didn't energise and motivate me.*

Like Jane, Dave adopted co-occupation as way to adapt to new contexts. He described returning and sustaining his membership of his mental health group

because of friends who also attended. This was to become the place where he felt the greatest sense of belonging:

> *"… Came along one night with no intention to stay, just for old times' sake. And I stayed, and I've got support ever since..."*

Dave also discussed how lack of occupation created through mingling at a party, could create an experience of exclusion for him:

> *"Where everybody is standing around with drinks, chit chatting and swanning around. I would find that very strange, hard, difficult, alienated. I'd find it a little bit easier if everyone was sitting around a big table. Having a meal and a bit of talking… because you're stuck in one place with the meal in front of ya and that makes things a bit easier."*

Dave reflected that this occupational possibility of dining could decrease his feelings of alienation with others, creating opportunities for inclusion. Tim too felt that collective occupation, would afford him a greater sense of belonging in his community. For instance, he felt an onus to give back to and be a greater part of his local community through paid employment:

> *"It might be my own ... sort of self that might need to change… if I got a job, and em, if I got, started teaching English in a, in a school, or something and started feeling better about myself, I might feel more comfortable in, in (name of home town)... I might feel like I've more to give, or something, I might get more involved or something like that. Whereas at the moment, I kind of, I haven't been getting involved, I haven't been doing much to help..."*

Through participation in occupations with others Tim felt that he could give back or help his community and be part of the collective to improve it. In summary, interactions with others were complex, sometimes creating inclusion and on other

occasions experiences of exclusion. Possibilities of co-occupation were important in determining doing and belonging.

For all participants enacting occupations within their secondary school environments produced mixed experiences of inclusion and exclusion, sometimes intertwined. For example, Tim described his experience of exclusion at secondary school:

> *"... I didn't get on the team there... and I felt a little bit excluded there… because it was all about football and it was kind of if you weren't on the team you were kind of, you weren't really you know, anything like, so that was like a little bit of exclusion there (pause)."*

Through being excluded from the football team Tim felt like he wasn't "anything". This poignantly illustrates the impact of the loss of occupation on his sense of being and belonging. Unlike Tim, Dave tended to attribute his feelings of exclusion in school to himself:

> *"... I just felt different. I think for the first few years of school, I was actually a bit slow picking up the writing and the maths. I think the first three years of school I literally looked out the window. Didn't really engage with the class, literally just looked out the window."*

Dave may have been excluded from fully participating in school because of learning difficulties. Had he been offered additional support this may have afforded him alternative occupational possibilities, creating meaning and greater inclusivity. Despite this, Dave described having friends and feeling included, adding:

> *"... I was afraid to share what I was, what I was going through with people… So, that made me even alienated from my friends. I obviously had some friends going through secondary school and eh college to some degree, but I hid it all inside."*

Similarly, Jane perceived her personal abilities as excluding during secondary school, but highlighted the environment as protective:

> *"... In getting on well in school, in the protected environment of home and down the road, em, I expected myself to go to, to College, which a number of my class did. Expected myself to get a qualification, I expected myself to get a career and a profession. And my expectations, like my father said you're not able for it, my, my expectations are not reasonable."*

Jane felt a sense of protection from school and it offered her potentially transformative opportunities for occupation, as she anticipated becoming a university student like her peers. However, this was restricted by established views from within her family, of her personally unreasonable expectations, unwavering to her mental health disability, culminating in her experiencing exclusion. In summary, secondary school experiences for participants, were both limiting and encouraging of occupational potential through environments which could be simultaneously enabling and restrictive.

Like their earlier education experiences, each participants' account of third level education which detailed more than one university attempt, created intertwined experiences of inclusion and exclusion. During their first university attempts the participants described environments from which they were detached, compounding their mental health difficulties. For example, Tim recalled his first university experience:

> *"And when I got to college it was like, I had this freedom you know. And I just, I wasn't ready for that freedom…. I just wasn't able to show up for college, and …. I got into this spiral of like fear about not showing up and then fear about not doing assignments, and just avoidance and escape..."*

The pressure of his course and his own unreadiness caused Tim to ultimately be excluded from participating in this meaningful occupation, a value shared by his academic family. Similarly, Dave recounted his first third level course reflecting on his experience of depression, loss of interest and resultant discontinuation of it:

"… I got very alienated, very unwell, especially the second one (year), I went into depression, that's when my mental illness really kicked in. But at that stage I had decided to leave that course because I realised, I had no interest in (name of course)."

Like Dave, Jane's first experience of university, exasperated her mental health difficulties, causing a crisis, excluding her from continuing and destroying her dreams of working in healthcare. She reflected:

"...I only did one year… I had a near fatal nervous breakdown at 19... And I ended up weeks in bed at home. And then I went voluntary into (name of psychiatric hospital) and I was six weeks there."

Despite these challenges all three participants returned to third level education, seeking more inclusive, often smaller college environments and choosing more meaningful subject content. However, these environments created a dualistic experience of inclusion and exclusion as demonstrated in Tim's account:

"... There was a bit of an immaturity, in, in some of them that I felt I'm not quite part of that. Em, but I did join the mature student society and kind of became involved in that, em... It was kind of good and got to know, got to know other mature students ..."

Jane recognised the importance of having the support of living with other students, choosing this intentionally, but also feeling excluded because of her age:

"... Although everybody else was 17 and 18 and I was 33, but that was a practical move in order to get the (name of course) done. And I had good… I had good support, a small class."

However, she proudly persevered, proving to both herself and her family that she could attend and complete university. Jane and Dave often described similar

difficulties socialising however their experiences contrasted, as despite returning to a different, smaller university and more meaningful course content Dave reflected:

> *"But I didn't belong their either. I loved the course, the, the material but I just was so poor socially."*

For Dave, the pursuit of education offered only an experience of exclusion attributing this to his social abilities. Dave did not describe accessing formal university supports but shortly after sought out his local mental health support group. To conclude, participants experience of occupation within educational environments afforded both feelings of belonging and exclusion.

Stigma emerged across all narratives, with participants having difficulty deciphering whether it was themselves or societal stigma, or a combination, which contributed to experiences of exclusion. Inclusion and exclusion often coincided within the same community or occupation. For instance, Dave reasoned:

> *"… When I do these things (mindfulness classes) … I find it hard to relate to so called ordinary people. Whether it's me being timid or shy or withdrawn or stigma... Also, I find that maybe, I don't have that much in common. Because I don't, I'm not married, I don't have children, I, I don't have a career, so my life situation is quite different from most people."*

He added later, how stigma has shaped the types of people he has connected with:

> *"So, the people I'm getting in touch with are other people with psychiatric problems or people who are helping people with psychiatric problems. Now this is great, I'm not saying that, there's less stigma than there used to be. There probably still is stigma around schizophrenia alright.*"

As stigma subsided for Dave, with time and increased community supports, he reflected on feeling ordinary:

"... I've just kind of noticed, in the last short while, year or two, when I'm getting my taxi back from where I do my shop for the week, back to my house, that I feel a bit more of an ordinary person, talking to the taxi man about this or that, or whatever…"

As a result, he sought new occupations and people outside of this network:

"... I'm starting to get a bit tired of the mental health, I wouldn't say system, or, but I suppose I would be psychiatric. Move in those circles and sometimes that can be, maybe it's a good sign that you're getting browned off with all that scene, eh and you just want to kind of like, I'm tired of mental illness now, I just want to move on and just enjoy life or whatever, you know."

Dave's mental health communities offered relief from the stigma pervasive in society. However, these too could restrict occupational possibilities or potential and resultant expression of his identity. Similarly, Jane found acceptance and belonging in her mental health support group. She adopted a formal role within the organisation in sharing her story, recounting:

"… I read a report in work and they said there is a huge stigma around schizophrenia. I would of told my story in (name of mental health support organisation) for about ten years and a couple of times I did it in public, and I would have said I have schizophrenia.

This used to be a meaningful experience for Jane, however the continued presence of stigma, coupled with her disabilities, appeared to have a surmountable effect on her participation in valuable, collective occupations:

"... I think, em, between my own withdrawn nature… you know feeling different with the physical disability, not being as strong as others, you know, doing ordinary things like the sponsored walks and the marathons, and you know things that others, out of the question."

Reflecting further she noted:

> *"… Well I did, feel a bit different and left out and that. And em, after reading that report, ... I said, now, I would not tell people I had schizophrenia, you know. I thought things were changing…"*

Later, Jane appeared to have differing perspectives on stigma as she recounted a media story of well-known figure being murdered by someone with schizophrenia:

> *"So, people with paranoid schizophrenia do, do, now I've never, but, do, do very bad things."*

I wondered if this was due to media portrayal:

> *"I don't really have an opinion, maybe they do. But em, I certainly don't feel the media lead, I don't feel the media lead negative towards the mentally ill."*

For Tim too stigma arose, occurring within his substance misuse support group, a place which he identified as affording him the greatest sense of belonging, reflecting how his status amongst his peers was diminished by his need for social welfare:

> *"Like, if you're not working your kind of, seen, your frowned upon a bit, em…. You know or on the dole, or whatever on disability or mental health problems or whatever and... … it kind of, you know I have a free pass, because I'm on disability, and stuff and, so it kind of makes you feel a little bit small you know."*

Like Dave, Tim was seeking occupations and people outside of his mental health sphere. Tim's meaning attached to working in his local mental health community was clear, using work-based tasks to support his future inclusion in paid employment. However, this also labelled him as different, anticipating how stigma could exclude him from paid employment:

"... you start to think oh, is it because I put (name of mental health community) on my CV and they looked it up and saw mental health and immediately said oh this guy is weird or something, you know."

Stigma permeated participants experiences of occupation within their environments, often occurring within environments where strong feelings of belonging were simultaneously expressed. This resulted in coinciding experiences of exclusion and inclusion.

4.4 Chapter Conclusion

Jane, Dave and Tim chose to use occupation in a quest, to experience life normally and healthily within receptive and meaningful community environments involving neighbours, peers, friends, families and wider neighbourhoods. These occupations took different forms, rich in meaning and value, and created opportunities to connect with others and experience belonging. However, experiences were often more complex, challenged by exclusion and stigma, leading to the simultaneous experience of being part of a community but identifying as different or marginalised.

Chapter Five: Discussion

5.1 Chapter Introduction

In the findings chapter, the participant's stories were presented, offering snapshots of significant moments within their lives. Their narratives reflected a desire for change and the meaning held in occupation to realise capabilities and shape identities. Theses identities were shaped by the participants and further, by the people and places in their environments, as well as by certain perceptions about normality or ableism within society. Answering my research questions (Figure 1), two distinct themes emerged from these findings, the first detailing the function and meaning of occupations for participants, while the second illustrated how participation was afforded or restricted arising through inclusion or exclusion experiences.

5.1.1 Figure 1: Final Research Questions

1. How do people with self-reported mental health disability participate in or experience occupation in their local, familiar environments?
2. Do people with self-reported mental health disability express feelings of belonging to their community and other environments through enactment of occupation?
3. How do participants feel their environment has influenced their occupational possibilities?

The findings of this study add to the understanding of occupation as it relates to health for people with a mental health disability. Further it illuminates experiences of belonging, including encounters of both inclusion and exclusion within their communities. In this chapter, I will discuss these findings amongst existing literature.

5.2 Normality, Occupation and Participation

How occupation is experienced by people with disabilities, applied in OT and theorised within OS, is paramount in adding to the knowledge of this complex phenomenon within the fields of health, disability and human rights. The following section will explore underlying attitudes and assumptions regarding perceived normal participation and the impact of the choices made by participants regarding their occupations. This first section is intended to discuss the first two research questions concerned with how the participants participated in occupation, and their subsequent feelings of belonging. While the second section in this chapter, addresses in more detail the impact of the participant's environments in creating experiences of belonging.

5.2.1 Perceived Normalcy attached to Occupation and relatedness to Identity

In response to the first research question asked, the participants in this study, experienced occupation within their local environments as normalising, a finding consistent with those of other studies exploring the perspectives of people with disabilities (Bartolac & Sangster Jokic, 2018; Blank et al., 2015; Gould et al., 2005). Occupations were normalising for participants in this study, because they offered stability, routine, familiarity and continuity when mental health disability had disrupted their lives and resultant anticipated identity trajectory. Participation in occupation also meant a way for participants in this study to express their capabilities, identities and reflect their values and beliefs. Further, their participation in occupation was meaningful because it created experiences of acceptance, recognition and security from others. Occupations the participants articulated as normalising included paid employment, volunteering and supported work within a mental health community which attributed to maintaining a productive identity. Maintaining a productive identity was highly regarded by participants in offering stability, routine and continuity, expressing capabilities and reflecting values.

However, these were meaningfully sought too through occupations, such as art, music and craftwork, important to participants in upholding creative identities.

Occupations identified by participants in this study such as paid employment, volunteering and work-based activities within the mental health community offered routine, stability and continuity of a productive identity. However, overall perceived normalcy ideas resolutely resided within the occupation of paid employment at the expense of minimising important or meaning attached to other chosen occupations. This emerged in how Jane reflected on her current employment, how Tim imagined future employment and, in the ways, that Dave reflected on his past lack of opportunity within paid, competitive employment. Overall, being in paid employment meant that participants could be perceived both by themselves and others as normal. Paid employment created opportunities for routine, and recognition from others while reducing feelings of difference because it was normalising. For example, in this study the benefits received by Jane through paid employment within a highly regarded community service, included status and inclusion, adding that her current workplace was a *"God send".* This is echoed in the findings from Blank et al. (2015), where participants denoted involvement in work to feel normal and experience belonging.

Exploring the presence of perceived normality ideas attached to paid work, within western society, an emphasis on gaining competitive, paid employment is documented alongside an intricated relatedness to identity (Blank et al., 2015; Kantartzis & Molineux, 2011; Unruh, 2004; van Niekerk, 2016). Although it is important to note, that research findings referenced, in this instance, emerged from larger Western countries, cultures which may have some similarities, but do not exactly reflect the nuances of Irish culture. Relevant to the current study, Irish people with disabilities are less likely be in paid employment as compared to those without disabilities, with the NDA finding only 31% of people in employment compared to 71% of those without disabilities, despite the former's expressed interest to work (Department of Justice, 2017). However, this report did not specify disability type, consistently adopting the term "people with disabilities" perhaps due to the wide

reaching intended outcomes of this strategy [6]. Focusing on Tim's narrative within the current study, he discussed mixed feelings about his current employment status, which appeared to compete with his long-established identity as a contributing, paid worker. Although, expressing that he felt like he was working in his mental health community through his active engagement in work-based activities, this did not give him a complete sense of normalcy, jarring with his previous identity. However, on reflection Tim was cautious in any return to paid employment; remembering how his participation was impacted in the past, by periods of mental health distress, with his health a pertinent consideration in any future work endeavours. Like Jane, Tim's efforts to return to paid, competitive employment appeared contingent on sourcing a supportive workplace offering meaningful work but also supporting his health. In her research exploring the experience of work with people with a psychiatric disability, van Niekerk (2016), highlighted two differing processes of identity formation. One of these encompassed a flexible approach to those life disruptions caused by psychiatric symptoms, supporting lasting participation. Resonating with Tim's experience of work, is van Niekerk's (2016) other finding where some participant's in her study strove for a stable identity, playing out as restricting return to work due to the ongoing presence of mental health symptoms or concern about relapse. However, it is also important to consider, if the value attached to returning to work for Tim could be influenced by embedded Western ideals around monetary gain and economic contribution to one's community (Blank et al., 2015). This ideal, too may have impacted Dave's reflection on his lack of access to paid work, whereby he minimised his involvement in other productive occupations, such as vocational programmes over the years. However, I am again, cognisant that Tim and Dave's experiences are situated within Irish culture, and so may be impacted differently than Blank et al.'s (2015) findings, emerging from the United Kingdom.

The extent to which paid employment was valued above all other occupations in experiencing normality for the participants in this study, was evident in Tim's view

[6] I returned to this report to clarify the definition of disability used, however I was unable to locate it. The report refers to disability within the 2011 Irish Census. On exploring the types of disabilities considered within the 2011 Irish census *"Psychological or Emotional Condition and Other Disability"* was one of 7 possible categories under question 16 of this census seeking data about *"long lasting conditions"* (Central Statistics Office, 2020).

of his development of a routine oriented around non-work activities. During his discussion of his difficulty adapting his routine to schedule a meditation class, Tim minimised his efforts by commenting on his schedule as an unemployed person. He compared it to the busyness, and perhaps importance of the schedules of those around him who were employed. It appears, because his practice of meditation involved *"doing"* and as such was not necessarily visible to society, that this occupation was undervalued or discarded. Thus, building an identity outside of that of *"paid employee"* was challenged by these standard conventions. Kantartzis and Molineux (2011), may offer some insights into this, in their discussion challenging the emergence of knowledge and assumptions about occupation from a narrow, Westernised viewpoint. They describe how the familiar, time constrained working day structure and resultant periods for rest and free time emerged within Western culture following the success of the industrialisation period (Kantartzis & Molineux, 2011). The authors argue that it was this widely accepted societal construction of time, established during the era of industrialisation, which influenced the prominent categories, that are: self-care, work and leisure. Although, their discussion should be metered when interpreted within an Irish context, the categories described have infiltrated my clinical practice, a convenient but inauthentic way to explain the complexity of occupation to those with whom I work. Kantartzis and Molinuex (2011) illustrate how leisure was determined by society something to be earned by those in paid employment and harnessed for personal progression. It has also been labelled ableist, class dependent and irrelevant to non-Western cultures (Hammell, 2009). Leisure as conceptualised by these studies would appear relevant to consider for people with a mental health disability living in Ireland. Although there may be differences, as with every unique culture, this provides some insight into underlying norms regarding the division of time.

Yet, participants in the current study not only sought experiences of normality through paid work but through regular experiences of being creative both alone and collectively with others. Creative occupations took different forms but included craft, art and music. These occupations, often pursued in the company of others, offered participants enjoyment, connectivity with their social worlds and overall a sense of

acceptance. These valued occupations enabled their participation in wider society. For example, Jane highlighted her membership of her women's group and the multiple forms of creativity she experienced through it. She engaged in the process of creating with her peers but also produced items she could gift to others. Thus, the function of this occupation was to offer participation and belonging through the experience of normality in doing the same and being with others, while affording recognition through her creative end products. Describing one part of her larger study investigating play and creativity in adults, Blanche (2007) ascertained that creativity could materialise through a variety of forms with some participants finding greater meaning in the process of participation in creative occupations and others in the outcome produced. Creativity within ordinary everyday occupations, offered many participants feelings of excitement, pleasure, and freedom while also including increased energy and spiritual experiences (Blanche, 2007). Comparing Blanche's (2007) findings with those of the current study, participants did not mention energy and spirituality, but did attach feelings of excitement and pleasure. Tim pursued music writing and practice alone, but also engaged in performing with his friend, persevering with his musical performance because it was *"the right thing to do"*. He also engaged in spontaneous busking in his local area, being part of his community through interacting with passers-by. His creativity, as pronounced through music took various forms, all of which offered meaning, being and belonging.

Through these meaningful occupations, Dave, Tim and Jane, appeared to move outside of their identities of having a mental health disability, experiencing normality and becoming part of their social groups, as their participation was enabled by receptive people and places. For example, Dave described the *"natural"* environment of an art class within his peer led mental health group. Through the medium of art, the space was transformed whereby participants could be quieter and more comfortable. Within this, Dave appeared to associate being quiet as awkward, hinting at abnormality. However, a quieter attitude went unnoticed, in fact was likely preferred, in order to participate in art offering security, acceptance and ultimately feelings of normality through a creative identity. This finding resonates with that of Reynolds (2003), who analysed the narratives of group of disabled

women, capturing their beneficial use of the creative occupation of textile arts as they navigated life with chronic illness. One such benefit was their creation of artistic work within their social groups, which validated their capabilities both to themselves and others, supporting them in showcasing identities beyond that of disabled (Reynolds, 2003).

Further, Nagle et al. (2002) found participants in their study, related occupational participation to health, noting the duality of this relatedness in both nurturing and disrupting health. Health was negatively impacted when periods of illness acuity inhibited participation, apart from that of participation in creative occupations. Creative occupations were pursued due to increased inspiration felt through them and to alleviate distressing symptoms (Nagle et al., 2002). This was a finding, that chimed with Jane's reflection in the current study, as she felt going to a concert with a group of others, was enjoyable, and helped her take her mind off things, summarising that this normal occupation was reassuring to a life disrupted by mental illness. For, Jane this did more than just manage symptoms, it offered belonging and normality: "*you're with people you love, and other people do it".* Consistent with, Blank et al.'s finding that participants in their study felt a sense of connection with others and belonging though occupations other than that of paid employment (Blank et al., 2015).

Perceived ideas of normalcy within creative occupations were evident when Jane was urged to return to her women's group by her Psychiatrist who identified that she was spending too much time with her parents. Although this appeared to me, as an occupation attributed by another as normal and imposed on Jane, she did not perceive it in this way. She spoke about her return to her women's group and how engaging in craft occupations *"carries you through",* that you don't have to engage in much chat with others and is relaxing as a result. Within this example, ideas of normalcy emerged from both Jane's personal standpoint and from significant others, but still, participation was profoundly meaningful rising above these perceived norms. Offering further insights into perceived normalcy in practice, Njelesani, Teachman, Durocher, Hamdani and Phelan (2015) found that the realisation of true client centredness was impacted by inherent assumptions about

what occupations are possible for clients such as the *"prevailing values concerning normalcy"* (p.253) held by occupational therapists. Expanding, the authors assert that permeating ideas of what are normal occupations from within OT may dissuade an occupational therapist from choosing relevant occupations, thus limiting a client's occupational possibilities. The authors adopted *"a critical occupational approach"* in their review of key concepts related to client centredness and subsequent discussion of three studies, each pertaining to specific group experiences of different life transitions (Njelesani et al., 2015). The authors provided instances where occupational therapists' reasoning regarding the developmentally or socially appropriate pursuits of clients has barred consideration of unique client preferences in informing therapeutic goals and endangering client centredness.

Within the current study, participants found connecting with others highly meaningful and valuable. Being with others or being part of society through occupational possibilities that were perceived as normalising were the vehicle through which to achieve this. However, ideas of normality did not emerge solely from participants' experience of being *"unwell"*, they appeared too, to stream from significant others, family and friends, as well as societal views. The impact this had on participants' participation was complex and will be discussed further in this chapter in the next section.

5.2.2 Occupation: What is Health Promoting and Health Diminishing?

When considering the findings, in this study, the traditional categorisation of occupation would appear insufficient, for the meaning behind participants' occupational choices do not fit neatly into one of these three categories. Within this subsection I will discuss how they also chose occupations to promote their health including accessing occupations which were restorative and spending time with others. Western valuing of productivity (Clark, 1997; Hammell, 2009; Howell & Pierce, 2000; Kantartzis & Molineux, 2011; Zemke, 2004) and independence (Njelesani et al., 2015; Sakiyama et al., 2010) are powerful forces in how occupations

are chosen whether determined by individual preferences or infiltrated by societal expectations. The traditional categorisation of occupation into three primary areas of self-care, productivity and leisure continues to be reviewed and debated (Hammell, 2009; Howell & Pierce, 2000; Kantartzis & Molineux, 2011; Unruh, 2004). Hammell (2004a) notes through adoption of greater qualitative research methods the contribution of those experiencing disability toward our theoretical OT development is felt. How the participants in this study experienced their chosen occupations as health promoting or diminishing, as offering space to just "be", while also shaping their identities through becoming and belonging will be discussed in the context of relevant literature.

The participants in this study described their positions in time and space, attending to their mind and bodily needs for rest, food and energy as beings. They chose to engage in restorative occupations such as sleep, meditation and eating which allowed them to "be" in the moment and attend to their immediate health needs. This tended to give rhythm, meaning and stability to their routines, given the priority bestowed by all of them on health maintenance and promotion. A priority shared by participants with mental health disabilities in other studies (Blank et al., 2015; Nagle et al., 2002; Sutton et al., 2012). Often during the interviews, I felt keenly the force of disruption created by mental health disability, for example when life was interrupted by a new medication or a hospital admission. During these periods, the participants described adjusting their occupations to protect their health, creating possibilities for restorative occupations and using their environments to facilitate this access accordingly. For example, Tim chose to spend more time away from others, in his room playing video games. Although Tim clearly articulated this occupation as healthy, his perception was challenged by societal beliefs that this was unhealthy. He felt shame about having to choose this, in his own words *"I'm not proud of that"* but persevered, realising his right to this choice, despite discrimination from within and outside himself. Choosing this path, seemed risky in that Tim considered how it may have appeared outwardly unhealthy or unsupportive to his recovery, increasing potential for marginalisation and further deprivation if he wasn't supported to access other possibilities for occupation. Playing video games, afforded Tim enough doing, creating a space for him to be and facilitating his becoming recovered. This resonates

somewhat with what Sutton and colleagues (2012) identified as a state of *"partial engagement"* whereby participants reflecting on their mental health recovery described engaging in occupations that were simple and not too demanding, allowing for some reconnection with their bodies and the world around them. However, the use of the word *"partial"* conjures ideas of ableism, denoting it as incomplete or perhaps irrelevant. Conversely adopting the term restorative, implies the person is agentic in their participation.

Accumulating research indicates the need for people with a mental health disability to be able to adjust or regulate the amount of occupation they are exposed to protect their health and preserve meaningful participation (Gould et al., 2005; Lipskaya-Velikovsky et al., 2016; Nagle et al., 2002; Sakiyama et al., 2010; Sutton et al., 2012). In the study by Gould and colleagues (2005), participants retreated from occupation to a place of *"coasting"* in order to survive the forceful impact of their acute mental health symptoms and new diagnoses. Further, Lin and colleagues (2009) in their study exploring the occupational engagement for forensic clients living in the community, found participants preferred to be part of occupations with others through indirect interaction.

Adding insights into the form of restorative occupations, Howell and Pierce (2000) in their research about the occupation of quilt making described restorative occupations as having:

> *"... Strong routines of simple, even repetitive, actions and often appear to be high in pleasure, as well as restoration"* (Howell & Pierce, 2000, p. 69).

For all participants in this study, choosing meditation was restorative, protecting health and giving shape to their daily routines through regular scheduled practice. Meditation was an occupational possibility facilitated by the participants' home and community environments given the resources available to practice alone or within a group setting. For example, Tim and Dave both included meditation within their daily routines while also seeking group experiences. Although Jane was not practicing routinely, she sought out meditation and personal reflection amongst parishioners

within her local church through silent prayer. Consistent with the findings of Chisman and Brooks (2018) indicating a relatedness of the concepts of being and belonging through the occupation of mediation, Jane reflected that the meditation would support her in managing her distress and promote social connections through *"keeping the head".* It also provided an opportunity for her to spend greater time with the community she expected to return to when assuming a greater carer role for her parents. Similarly, Dave who moved beyond the doing of meditation to a place of acceptance and belonging, realised his place in the world as a contemplative person.

Generally, the wider cultural context is important to consider when discussing and understanding how occupational possibilities are afforded or restricted for people with disabilities in their environments. For example, reflecting the influence of the socio-political environment within an Irish context, Moloney and Rohde's (2017) qualitative research of a community football group for men with psychosis, was supported by the national mental health policy, AVFC which documented the benefits of physical exercise and belonging. However, the authors highlighted that AVFC did not actively direct mental health services to offer opportunities for football thus restricting access to this health promoting occupational possibility. Returning to Kantartzis and Molineux's (2011) examination of occupation within Western society they identified four prominent dimensions of this construct as represented from this Westernised perspective, that is: occupation is active, purposeful, temporal and meaningful. The authors question how this conceptualisation relates to diverse groups and cultures outside of Western society (Kantartzis & Molineux, 2011), considering risks in perpetuating repression and disempowerment to those who possess differing values, attitudes and cultural beliefs (Hammell, 2009; Kantartzis & Molineux, 2011). Reflecting on my experiences in clinical practice in Irish mental health I have often received referrals for *"activation"* as if the underlying assumption is that through observed doing, a person's health is evidenced. Further, as Kantartzis and Molinuex consider the implications this has for groups of people who are unable to showcase this characteristic of doing due to some physical or mental health disability, an assertion shared by van't Leven and Jonsson (2002). While, Bartolac and Sangster Jokic (2018) documented participants' experiences of loss of control over

their occupations when requiring the assistance of others leading to deprivation arising from restricted participation at personal and contextual levels. Offering further insights into the impact of culture on occupation, Larson and Zemke (2003) in their review of the social coordination of occupation in time, note that we inherit attitudes and beliefs from our families regarding the appropriate use of time, impacting the importance attached to activity selection.

Considering other available literature in relation to choice and being with others, Christiansen (1999) purported that through personal choice identity is expressed. However, as Phelan and Kinsella (2009) point out, choice features frequently in identity theory and implies that individuals can choose their occupations, failing to attend to the common misuse of power disrupting occupation, disregarding rights to participate and disallowing autonomy in selection of occupations. Additionally, Hamer et al. (2017) in their study exploring experiences of exclusion from the perspectives of mental health service users, found that participant's felt they had to be allowed access to the ordinary occupations important for their participation.

However, unlike Phelan's (2009) perspective and Hamer et al. (2017), the participants within the current study exercised choice within the occupational possibilities available to them. This may have been due to their experiences of inclusion, enabling participation, such as the support received from their mental health support groups. Rebeiro et al. (2001) discussed how experiences of belonging could enable being and becoming. Perhaps this is a finding, shared with the current study in that participants' making meaning with others, facilitated belonging and promoted choice. Laliberte Rudman (2002) suggested that occupational possibilities when absent could limit identity expression, but when present could create potential for its development. Further, finding that participant choice and control were necessary to afford beneficial outcomes from occupational participation, as one participant expressed how her choice of volunteering would not have had the same positive impact to her identity had she not chosen it herself (Laliberte Rudman 2002). For example, within this study, Tim and Jane's possibility of attending third level education shaped their identities as capable and achieving third level students.

Particularly, Jane highlighted the importance of this being her choice, despite prevailing attitudes from others regarding her ability. Lindsay et al. (2018) concluded that youth with disabilities and without had different influences on their occupational potential. Citing Wicks (2005), they describe occupational potential as:

> "*.... People's capacity to do what they are required and have opportunity to do; to become who they have potential to be. This concept recognizes people's individual capacities as well as constraints on their occupational options"* (Lindsay et al., 2018, p. 323).

The above considers personal capability unlike Laliberte Rudman's (2002) definition of occupational possibilities which focuses on the contextual realisation of occupation as *"ideal and possible"* (Laliberte Rudman, 2002, p. 55). I think the latter is more applicable to this study's findings, given the privileging of some occupations above others, coupled with participants' experience of exclusion and stigma, obscuring their potential.

The above studies offer insights into the demands placed on people with disabilities as they navigate a society imbued with ideas about normal and expected participation patterns. The participants in this study, despite restrictions placed on their occupational possibilities found experiences of belonging, enabling their participation and their choices ultimately promoting their health. When considering how to conceptualise this, occupational possibilities is a term which considers to a greater extent the environmental impact on identity and choice. In the remaining pages of this chapter and in answering my second and third research questions, I will attempt to illustrate how participants' occupations were situated and how transactions with their environments produced experiences of participation that were inclusive and exclusive.

5.3 Meaning Making and Experiences of Inclusion and Exclusion within Community

Occupation was viewed as a conduit through which meaning was articulated and built upon to form identities. The routines the participants described were organised around specific times, places and people. They chose occupations and adjusted them accordingly depending on the time available to them, the needs of others or the meaning elicited. These choices reflected narratives which were focused on change making and would primarily reflect what Polkinghorne (1996) deemed an agentic personal story. However, encounters with environments or attitudes that undermined identity and generated experiences of difference or exclusion, could divert and disrupt participation. Answering the remaining research questions, the following section will show how participants went about creating meaning within physical places, with objects and amongst others. Further I will explore their experiences of inclusion and exclusion within these physical and social contexts, interweaving pertinent scholarly perspectives and research studies.

5.3.1 Meaning Making: Within Places and Amongst Others

In this study, Tim and Jane were in the process of meaning making within different points in their lives, whereas Dave was considering moving beyond his existing communities and groups toward new frontiers. Meaning making within places and amongst others shifted for participants depending on their sociocultural and physical spaces, as well as the meaning attached to these and their occupations. Additionally, the participants meaning making shaped their current and anticipated identities. Rowles (2008), in his autobiographical thesis exploring how personal environments cultivate meaning over the life course, identified four domains of meaning: through engaging in occupation, loving others, exerting our autonomy and lastly, being part of the universe. Rowles (2008) explains how these domains shift depending on each person's life trajectory and the places where this unfolds. He asserts that through

affecting and being affected by our environments life courses and meaning are shaped.

For Jane, she currently negotiated her daily routine with her parents in supporting them in their participation as well as her own, organising occupations around meals and care tasks. This routine was not just important for Jane's health but for her identity as a daughter and carer. She noted the need to make a greater sense of community for herself as she moved to be closer to her parents and support them into the future, anticipating how her paid worker role would diminish in response to this lifestyle change. Jane created greater meaning within her home community by attending her local church, being part of the physical space as well as being visible to her community through mass. She enjoyed the solitude of praying by herself, amongst others, and sought additional contact in connecting with others at the church door when the service was over. Further, Dave described the importance of his everyday routine and his use of to-do lists particularly in managing domestic occupations, to give him a sense of pace, satisfaction and restoration. Reflecting on the benefit of this to his health by contrasting this experience with how he felt when rushed or under pressure. As he reflected further, Dave highlighted how his mental health had dominated his life. But that now he was seeking to move beyond this, using time out and breaks as a way to engage in contemplation identifying a particular place within his home where he could look at nature and be contemplative. This created meaning for him as he began to value his contributions to the world by dedicating time to this, reflecting his emerging identity as a Contemplative person. Further, Tim chose to walk in his local seaside area for his observation session, with this natural setting offering him peacefulness and relaxation while also being a place where he walked with others to maintain contact with friends or to show his area to visiting friends and family. As Hitch et al. (2014b) described:

> *"The relationship between being and becoming can be the site of powerful human experiences, which draw together who people are and who they can be"* (Hitch et al., 2014b, p. 252).

Thus, places were significant in suffusing the participant's lives with opportunities for meaning making, reflecting sociocultural histories (Jackson, 1996) and inspiring future selves through being and becoming (Hitch et al., 2014b).

Objects too created meaning for Jane, and Dave, often signifying evolving identities. For example, Jane highlighted the role a pew played in her local church in helping her to find her way back. While another object, a painting, had the potential to transform Jane back to meaningful time and place with her friend in her women's group. Jane's experience also created a new identity amongst others as she gifted her work to family. This use of objects in this way, enabled her participation in meaningful occupation becoming visibly capable to herself and her family members, enhancing an experience of belonging. As Reynolds (2003) noted:

> *"Creative artwork may hold particular potency for reclaiming self and identity, because it enables self-expression, and provides a legacy of visible lasting products in which the person can take pride"* (Reynolds, 2003, p. 119).

Dave accessed multiple spaces in which to meditate or to contemplate the world including group meditation, his own home and natural spaces. Dave identified a specific tree within his local park where he could get away from everything. He reflected how connecting with nature and feeling belonging to both places and people was peaceful and held spiritual meaning for him, a finding reverberating with Rowles' (2008) concept of *"nurturing meaning"* through using our personal environments to create settings or spaces for:*".... immersion in the reverie of simply being"* (Rowles, 2008, p. 133). Dave's access to these spaces afforded him the opportunities to be and become a contemplative person.

Meaning making for participants in this study did not occur in isolation from others but in collaboration. However, the amount or frequency of contact required varied according to each participant's preferences, needs and past experiences of exclusion or stigma. For example, Dave chose certain mainstream community groups around meaningful occupations, such as meditation or art therapy. These choices

afforded him opportunities to be part of his community while adjusting his need for social contact to a level that he found comfortable. He recognised the relatedness between his health and being with others, a finding consistent with that of Nagle et al. (2002).

However, this contrasts with findings from Lipskaya-Velikovsky et al. (2016) where people with mental health diagnoses as compared to those without, spent greater time alone when participating in occupations, querying that this could indicate greater experiences of exclusion. Using the Adults Subjective Assessment of Participation (ASAP) the authors measured the diversity and intensity of their participation in 42 activities. However, to my knowledge choice was not investigated in their study, and so the results, do not consider which factors, personal or others influencing these choices. The authors, however, acknowledge the need to consider context within OT intervention to focus on the role of others in participation. Although time use was not measured or compared objectively in the current study, Dave, Tim and Jane sought out occupations with others at varying degrees of frequency and preference, viewing both time with others and time alone as health promoting. For instance, Tim discussed his return to spectating at sports matches, encouraged by his peers in his mental health support group. These findings offer additional insights through the participants' own words on the reasoning underlying their selection of meaningful occupations.

Further, Jane anticipating a significant change in her environments in assuming greater caring responsibilities for her parents, was spending increased time in her home community, creating opportunities to seek out occupations which could generate feelings of belonging. This was despite often feeling very frightened of others. Jane recognised her need for support in being with others and the meaning this held for her in being part of her community and through this, supporting her parents to live at home for longer. For instance, Jane detailed how she went out into her community with a friend or family member using their skills and experience to support her in managing her fears with others and enabling her participation. She articulated this clearly in her choice of mass within her local church identifying it as central place from which to form new and strengthen existing connections, and one

in which offered predictable amounts of contact with others. Zemke (2004) attends to *"place making"* as an occupation defining this as:

> *"... The act of creating and maintaining places (for example, homemaking) – a human occupation often in collaboration with others"* (Zemke, 2004, p. 613).

She describes this as when humans bestow space with accumulated meaning and experience over their time spent there and their memories becoming associated with their identity. Further she adds that we rely on both times and places to "... *allow us to 'be' and to 'do' our selfhood through our occupations"* (Zemke, 2004, p. 613), confirming like others, the relationship between what we do and who we are or who we might become (Hitch et al., 2014b; Jackson, 1996; Rowles, 2008).

All three participants in this study created meaning through a sense of belonging and community sourced from within their mental health support groups. Such a degree of belonging and community had not yet been experienced by them prior to locating their groups. Both Dave and Jane were attending for several years, Tim less so. However, all stressed the value and significance these groups played in their lives, arriving unexpectedly, during periods of distress and often indicating a turning point in identity. Dave, Jane and Tim communicated a sense of relief in finding others with shared experience, feeling acceptance and belonging there. Rebeiro's (2001) findings demonstrated how such an affirming environment underscored each person's self-worth and resultant confidence to return to and continue participation in valued occupation. This finding was reflected within the current study, for example in Tim's experience of returning to meaningful occupations with encouragement and support from his group members. Participants in this study expanded their roles within their mental health support groups, moving beyond membership, assuming leadership or organisational positions. Demonstrating the strength of impact of such groups, is Rebeiro, Day, Semeniuk, O'Brien and Wilson's (2001) study, evaluating an occupation based mental initiative, the Northern Initiative for Social Action (NISA). An occupational therapist and consumers of NISA identified how the being, becoming

and belonging needs of members were met by this initiative. Being was achieved when heard and accepted by others experiencing increased self-worth, belonging in sourcing a place to be, and fostering becoming through the opportunity to participate in meaningful occupation (Rebeiro et al., 2001). Although Jane and Dave moved away from their peer support groups overtime, overall, for the participants in the current study, their mental health support groups appeared to facilitate the right to be. This peer support positioned them as agents of change and further enabled their participation in novel occupational possibilities in more demanding and unpredictable environments.

5.3.2 Participation: Experiencing Inclusion and Exclusion

While participants in the current study felt they were responsible for taking control of their lives and managing their health, they also recounted experiences of stigma and ableism impacting their participation in a variety of occupations and resultant occupational identities. Complex encounters ensued, creating experiences of being part of community but remaining different, sometimes limiting occupational possibilities and feelings of belonging. The dialogue regarding the health promoting aspects of occupation evolves (Hammell, 2009; Kantartzis & Molineux, 2011) as prevalent ideas of ableism are continually contested (Asaba & Jackson, 2011; Salmon, 2013). Pervasive normative discourses within society may compound individual experiences of difference already felt because of distressing mental health symptoms (Bryant et al., 2004; Nagle et al., 2002). This can result in conflicted responses of secreting differences or shaping trustworthy selves to experience inclusion (Hamer et al. 2014). The experiences of inclusion and exclusion for participants in this study will be discussed herein, against a backdrop of current literary perspectives.

Perspectives on disability from members of ENUSP, in their ongoing discourse involving the social model of disability draws attention to the complexity of the relationship between disability to madness and distress (Spandler & Anderson, 2015). Choosing which identity, that of disabled or that of mad, uncovers more

complex reflections regarding the conceptualisation of *"mental health impairment",* (Spandler & Anderson, 2015). Additionally, Russo and Wooley (2020), comment on the use of the term psychosocial disability in Eastern parts of the world which may serve to advance the UNCRPD, while from their Western, European perspective, note the diversity of the terms used and their stance to avoid use of labels or definitions. For example, for the participants in this study they named their diagnoses, and all continued to access formal, medically led mental health services as well as peer support groups[7]. They identified clearly, periods of mental health distress which prevented them from participation in occupation. This coupled with societal attitudes compounded feelings of difference and resultant marginalisation from their communities. For example, Dave reflected on how a new identity was emerging for him, that for much of his life was obscured by managing his mental health disability and resultant years of primarily interacting within the *"psychiatric scene".* Dave described himself as having a mental illness and as *"psychiatric".* However, he also recognised the impact, for him on prolonged interaction within this sphere, describing sustained societal stigma and was now seeking novel occupations and people to move outside of this. This was an attitude also captured within Hamer et al.'s (2017) study, whereby the authors describe a state of exception occurring when mental health service users are excluded and marginalised from society as a result of having to hide their diagnosis or normalise their behaviour. The authors assert that this state of exception is:

> *"... Created by the dominance of the biomedical model approach to mental distress, their subsequent labelling, and the associated negative stigma and discrimination that dominates the lives of service users and is perpetuated by the rigid rules and norms of citizenship"* (Hamer et al., 2017, p. 78).

[7] Participants' use of peer led mental health groups demonstrates the value of peer support moving away from the medical model. However, all participants also valued the support from their mental health teams or mental health professionals. Thus, I think this illustrates the complexity of the relationship between madness and disability.

Further, they assert how stigma arising within and outside of service users could restrict access to valued social roles beyond mental health services (Hamer et al., 2017). Layers of underlying forceful social discourses regarding disability were uncovered and discussed by Asaba and Jackson (2011) through an individual's internal expression of this as combined with collective societal representations. In this study, in the context of an arising discussion topic of stigma, Jane recounted a media story regarding a murder committed by a person with schizophrenia, reflecting that people with this diagnosis can do bad things but stressed her personal separation from such events. Within her narrative, it would appear more dominant discourses about disability, usually negatively portrayed by media emerge (Asaba & Jackson, 2011) however, Jane commented that this specific event was unexaggerated and sparsely reported. Similarly, for Dave, he considers his difference from his peers in not having a wife and family, pondering how someone with a mental health disability could have a romantic relationship. He determines that this could occur only if it was with another *"psychiatric"* being too different otherwise due to the need for shared understanding of the impact of mental health. Reverberating with the dominant discourse uncovered in Asaba and Jackson's (2011) paper, surrounding the possibility of romantic relationships for people with disabilities, Dave's perspective was perhaps unconsciously impacted by widespread attitudes of what is and isn't proper for people experiencing mental health disabilities.

However, following on from this, as he began to feel *"more ordinary"* he reimagined his identity through the possibility of doing occupations with others outside of this scene, like the participant's narrative presented by Asaba and Jackson (2011), beginning to reject this powerful discourse. Additionally, the label of mental health disability is itself contested owing to its conjuring ideas of impairment stemming from the biomedical model (Spandler & Anderson, 2015). Feeling excluded led participants in the study with Hamer et al. (2014) to secrete their mental health identities in order to diminish stigma and any potential to be perceived as deviating from societal norms. A story presented from one participant illustrated the predicament he found himself in as he negotiated having to explain or hide gaps in his work history through revealing or secreting his mental health disability,

considering how both could hamper his participation (Hamer et al., 2014). In this study, Hamer et al.'s (2014) finding resonates with Tim's expectation that he would be found to be *"weird"* by potential employers who discovered his mental health community as a reference on his CV. Combined with his absence from the workforce this was colouring his belief, or lack of belief in his capacity or possibility for paid employment.

Salmon (2013) reflected on the idea of *"coming out as disabled"* as a process adopted by disabled youth in her study to challenge pervasive ableist attitudes. Within this, strategies for coming out as disabled included sharing experiences with fellow students, becoming politically active and participation in disability-based recreation (Salmon 2013). Reverting to the current study, in the past Jane reflected on her openness in sharing her story about her mental health history and finding belonging in her community mental health group. This appeared both satisfying and powerful for her in taking charge of her life, reflecting what Hamer et al. (2014) describe as a *"practice of inclusion"* (p. 207), a strategy used by participants in their study to use openness as a means to dissolve negativity in relation to their difference. However, due to her perception of rising stigma captured in published reports, she discontinued any public speaking regarding her mental health story. In this study, themes of normality featured heavily within Jane's narrative, evident in how she felt personal responsibility in managing needed changes to be normal like others. For example, through her visibility in occupation in returning to paid work, she evidenced this as an indicator of her health, to encourage her mental health service to discontinue a medication laden with adverse side effects. This may also be an example of what Hamer and colleagues (2014) described as service users being labelled as *"untrustworthy"* when experiencing objectification by others as a result of their mental health diagnosis and increasing exclusion. Similarly, through helping his parents, connecting with others through occupations and expanding his contributions to his mental health support group, Tim became more visible to those around him and felt more able to contribute to his communities as a result. Through demonstration of active participation in occupation each participant's agency was realised by themselves, their significant others and wider society.

Despite Tim's efforts to seek out numerous social networks and his expressed feelings of belonging within these groups, he described feeling disconnected from his hometown, describing another county as a place where he could express his creative spirit, where he had built up a strong network of friends and felt he belonged. In his second interview he reflected further that he would like to return, but that this could be difficult due to finances and was uncertain if this move could match his expectations when viewed from afar. Boland and Cunningham's (2019) critical reflection on occupation and homelessness at macro, meso and micro levels may offer insights into Tim's situation, although I am aware that the impact on his autonomy is far less than that of people who are homeless. The authors assert that OS is centrally placed to convey the interconnectivity of deficient environments with resultant unjust access to occupation. For example, at a macro level, they examine how definitions of homelessness can influence the accuracy of recorded occurrences and highlight assumptions regarding personal responsibility for its creation. Similarly, Edwards and Thomas (2018) reflect how the recovery model in mental health, as adopted by mental health services, locates the responsibility within the individual service user, infiltrated by neoliberalist ideas and reducing the focus on creating an enabling socio-political environment. Occupational therapists are called upon to consider how they can influence policy and its subsequent operationalisation (Boland & Cunningham, 2019; Edwards & Thomas 2018).

Irish people with mental health disabilities are at greater risk of poverty and homelessness owing to their lower rate of employment as compared to those without disability as reported within the National Disability Inclusion Strategy 2017 - 2021 (Department of Justice & Equality, 2017). In recognition of these risks, this strategy, alongside the National Housing Strategy for People with a Disability 2011 – 2016 (Department of Health, 2012) attempts to create inclusion for people with a mental health disability, by addressing their occupations (employment, household management, civic duties) but also the community environments in which they are located, advocating intergovernmental working to achieve key outcomes. This is somewhat realised within Irish policy but perhaps not fully operationalised, as illustrated by Tim's story. Tim's use of social welfare supports to manage his home

impacted his ability to choose his place and to expand his occupations, two of the domains listed earlier by Rowles (2008) as significant in nurturing meaning. Further, these are, as well as others, key indicators in creating "place" however, Rowles (2008) acknowledges how financial constraints can impede this creation and subsequent nurturing of meaning, highlighting opportunities to do so as critical. Additionally, Tim felt that through work he could contribute more to his community, perhaps gaining recognition, feelings of normality and offering increased connectivity with others, a finding also purported by Blank and colleagues (2015).

Within the *"state of exception"* described earlier by Hamer et al. (2017) a person's right to citizenship becomes jeopardised. During exclusion mental health symptoms become exasperated, with loss of agency following, as the dominant psychiatric or medical model assumes control, enforcing norms (Hamer et al., 2017). The resultant experiences of community exclusion are deemed occupational injustices (Hamer et al., 2017). For example, Bryant et al. (2004) used the metaphor of *"living in a glasshouse"* to represent the complexity of the state of occupational alienation. Findings indicated that users of a day centre felt it provided security and comfort but could concurrently cause exclusion from society, if without its protection vulnerability increased (Bryant et al., 2004). This featured somewhat in Dave's reflection about his continued participation in the *"psychiatric scene"* whereby he no longer sought protection through these forums. Although in his situation he was seizing control over his occupations there appeared a strong sense of exclusion from other meaningful occupations available outside of these mental health specific settings. Similarly, Jane had moved beyond her support group finding increased meaning through her paid work and caring for her parents.

In this study, the participants' experiences of inclusion and exclusion coincided within their communities and chosen occupations. All participants in the current study sought greater inclusion or experiences of belonging, sometimes focused on expanding citizenship. For example, Jane referred to needing to be responsible and pursuing the right thing to do, sentiments shared by Tim who discussed his desire to contribute to his community through paid work. All participants in this study experienced exclusion, a finding shared by Hamer and

colleagues (2014) who reported that participants in their study were excluded by societal attitudes assuming their difference by their psychiatric label. Additionally, managing negative attitudes of others toward their physical or developmental disability was found to be unique to young people with disabilities negotiating the occupation of volunteering, when compared to their peers without disabilities (Lindsay et al., 2018). Capturing the essence of this, was Tim's experience of being labelled as different from other members of his group because of his access to a travel pass and his subsequent *"feeling small".* This also illustrates what Kantartzis and Molineux (2011) described as the need to have proven or earned one's status through paid work. Theorising identity processes as transactional with a person's social world, van Niekerk (2016) highlights how stigma could materialise as *"other"* challenging identity processes, coupled with the impact of disability in disrupting the continuity of a person's identity (Reynolds, 2003).

Hamer et al. (2017) adopted the term *"inclusion champions"* to identify individuals in a service user's community who facilitated their occupational justice. Participants in this study described feelings of belonging through accessing occupations within supportive environments enabling their participation. This was created through the mental health support groups or communities that the participants attended but also in the pursuit of varied occupations with significant, supportive others. Dave, for example, reflected on his perspective and experience of mingling in social events, preferring to have a meal around a table. The occupation of dining with others versus mingling was determined to be preferable because a bit of chatting was manageable, whereas mingling was unpredictable and alienating. Thus, occupation enabled participation and resultant experiences of inclusion. This is echoed in the findings of Bartolac and Sangster Jokic (2018) whereby, overall participants shared views of participation as:

> *"... shaping a sense of inclusion, where performing daily occupations was a means for fulfilling life roles, shaping identity and establishing one's position in a larger context"* (Bartolac & Sangster Jokic, 2018, p.7).

Additionally, Tim was embarking on a new occupation of volunteering to teach English. Encapsulating the above sentiment from Bartolac and Sangster Jokic (2018), Tim reflected on his aspirations to engage with his community to help improve it and to give back, visualising his use of teaching English, a highly meaningful occupation, as a mechanism to achieve this.

Past secondary school environments, and each participant's first experience of third level education were often excluding due to the combined impact of the emergence of mental health distress and stigma. Despite, feelings of exclusion and experiences of stigma within early experiences, further education yielded feelings of being part of society through meaningful occupation. For instance, all participants in this study attended third level education, sharing an experience of returning as mature students and experiencing belonging and success within these environments. However, it was not always inclusive, punctuated with often simultaneous experiences of exclusion. This was particularly apparent in Jane's university experience. Despite the trauma she experienced during her first university degree, Jane returned as a mature student to a smaller university closer to home, viewing it as vehicle through which to obtain a better job and ultimately, increase wellbeing.

In Whiteford's (2017) examination of third level education as a form of social inclusion, she articulates the benefits to people and society in the uptake of this opportunity combining one individual's narrative with the larger scale economic impact of increased participation. However, looking closer at the underlying ideals in creating access for diverse groups in third level education, such as those with disabilities, Whiteford (2017) highlights the complexity of perspectives. Some methods of increasing access such as *"aspiration raising"* (p.56) may perpetuate normative and neoliberal discourses, locating the change within individuals, undermining other forms of education or work (Whiteford, 2017). Tim's return to third level education was perceived as increasing his wellbeing and work opportunities while also reflecting his family's value of education. Although, like Jane he identified as different while there, noting his position as a mature student, he later embraced this identity through new occupations with other mature students. Dave, unlike Jane and Tim, persevered with his education despite his feelings of not

belonging, linking this with his own social abilities. Comparisons between each participant's university environment may have offered further insights into which specific settings fostered or constrained belonging and participation. Whiteford asserts that third level education has been overlooked within OS and implores scholars to research this occupation to uncover its transformative effects (Whiteford, 2017).

Although the participants in this study experienced inclusion, the frequency and potency of the exclusion they recounted requires further examination of the socio-political environment in its fostering of mental health disability. Townsend (2012) exhorts three lessons for upholding OJ: societal accountability to promote inclusion for all, strong governance, and policy formulation to stimulate operational changes within communities and finally, true integration of people with mental health difficulties in their communities. This action is not exclusive to mental health. Occupational justice can *"extend and complement understandings of social justice"* (Townsend & Wilcock, 2004, p. 80). Clarifying this, Hocking (2017) in her investigation of social justice and OJ, explores how social justice theories have evolved, highlighting historical deficits in considering health as a right for all, warning that failure to realise this right will perpetuate discrimination and exclusion of those with diverse health needs. Interlacing both concepts, she articulates how OJ captures the impact of social inequity and adversity through the identification of specific occupational obstacles restricting a person's right to participate and be included (Hocking, 2017). Like, Townsend (2012), Hocking (2017) too refers to capability theory, as a mechanism through which fairer social circumstances can be realised.

Bailliard (2016) cites Sen (2009), in describing the tenets of the CA, recognising society's role in promoting and upholding each person's capability to do, noting that functioning cannot occur without the necessary social supports (Bailliard, 2016). This involves critical reflection on a person's capability and removing biases regarding unshared values such as projecting an optimal lifestyle (Bailliard, 2016). However, it must be approached cautiously to ensure a culturally sensitive understanding of justice with documented attempts of addressing one injustice to find that further related injustices have ensued resultant from that action (Bailliard,

2016). The use of the CA is proposed as a framework through which to further understand OJ and politicise occupational participation and expose intentional and unintentional biases relating to this concept (Bailliard, 2016). While the CA is a model also advocated for by the mental health survivor's movement (Wallcraft & Hopper, 2015), Russo and Wooley (2020), discuss the challenges from this perspective in implementing the UNCRPD effectively, namely the longstanding divisions between grassroots organisations and psychiatry. While acknowledging how some professions have attended to social issues, they advocate for the development of a model, centralising self-knowledge of madness and distress which could capably implement the UNCRPD and reimagine the current delivery of mental health services (Russo & Wooley 2020).

5.4 Chapter Conclusion

The above findings indicate that visible use of occupation was considered normal, illustrating health and wellbeing to the self and to others. The most highly regarded occupation upheld both by the participants and society in offering normalising identities was that of paid work. Paid work seemed unattainable at times due to the obstacles facing participants in sourcing supportive environments, managing their mental health needs, and navigating stigma. Likewise, creative occupations were meaningful to participants in experiencing normality, offering ways to develop identities away from mental health disability and sourcing environments outside of mental health service structures which offered a sense of belonging. Participation in restorative occupations was highly valued by participants in managing their health and were important in expressing choice and identity. When engaging in restorative occupations participants were not always seen to be participating, despite the high levels of meaning experienced. Choosing occupations was important in promoting health but not always realised by underlying dominant, normative discourses.

Community was defined by participants through the physical places where they located their work, home, families, friends, and other occupations. The meaning created within these places and amongst others was substantiated by objects, shaped by time, and enhanced by being with people. All participants found belonging within their mental health support groups which offered opportunities to be, belong and become. However, the long-term impact of over exposure to these settings, with limited alternative opportunities, left one participant feeling frustrated and seeking novel environments to experience belonging. Injustices occurred through the prevalence of stigma appearing within individuals and wider society creating experiences of exclusion. However, participants strove for inclusion and were supported by people and places within their environment. Inclusion and exclusion did not occur in isolation but in a complex interface as opportunities for participation in occupation were created and restrained. In the next chapter, I will consider how these findings may contribute to existing research in relation to the experiences of people with mental health disability in relation to their occupational participation. Further, I will attempt to draw conclusions about the strengths and limitations of this study and identify future research needs in this area.

Chapter 6: Conclusion

6.1 Chapter Introduction

My intention in pursuing this research was to enhance academic understanding of occupation within OS through the generation of new knowledge about this complex phenomenon and its role within health and participation. Additionally, I hoped to improve occupation's clinical application in OT mental health practice. I attempted to answer my research questions in relation to the experience of occupation for people with a self-reported mental health disability in their familiar environments. Through analysis of their narratives, participants' occupational choices were illustrated, illuminating the impact of these on their identities combined with that of their unique sociocultural contexts. Situated in Ireland, the current research offers insights into occupational possibilities for people with a mental health disability living in this country. However, it is important to note that this may not reflect a more global experience of occupation for people with a mental health disability. In this chapter, I will evaluate this research project, suggest implications for OT practice and opportunities for additional research in OS, while considering its limitations.

6.2 Implications for Occupational Therapy and Occupational Science

In this section I will summarise the findings of this study drawing conclusions from within and combining this with existing research to strengthen results. I will convey the role of OT in operationalising these new theoretical insights into practice and consider future research avenues.

6.2.1 Perceived Ideas of Normalcy and Client Centred Practice

Perceived ideas of normalcy arose for participants in this study as they participated in occupations in their communities. For Jane, Tim and Dave, they recognised their abilities to participate in meaningful occupation which was normalising for them, offering stability, routine and continuity of their identities during periods of distress or in their mental health recovery. This included occupations which maintained a productive identity and those that allowed for creative expression, often enacted with others. Occupation as contributing to normalcy is a finding consistent with other studies exploring participation and disability (Bartolac & Sangster Jokic 2018; Blank et al., 2015; Gould et al., 2005).

Routine and stability were described by participants as features of paid employment, alongside recognition from others and reduced stigma because of a shared commitment to work. Access to paid employment tended to be endorsed, above other occupations by participants in this study given the potential to achieve a perceived normal identity. This finding of the importance of paid work in shaping personal identity is echoed in existing literature (Blank et al., 2015; Laliberte Rudman & Aldrich, 2017; Unruh, 2004; van Niekerk, 2016). As well as paid employment, creative occupations were important for participants in this study in offering enjoyment, connectivity with their social worlds and overall a sense of acceptance. Creative occupations presented possibilities to reach greater proximity to a perceived normal identity and ultimate feelings of belonging within their communities, a finding which confirms the importance of creative occupations as a means for identity expression, as found in other studies (Blanche, 2007; Reynolds, 2003). Through striving for conventional participation within paid employment and creative occupations, participants in this study experienced or anticipated experiences of belonging.

As mentioned in other chapters, ideas of ableism and stigma frequently disrupt the participation of people with mental health disability, creating occupational injustices. Client centredness is a celebrated aspect of OT practice and theory (Hocking, 2017; Law et al., 1995; McCormack & Collins, 2010) and as such we are called to action by our global professional body to *"…enact our client-centred*

aspiration…" (WFOT, 2019). However, client centredness continues to be threatened by perceived ideals that are not responsive to its values (Hammell, 2013; McCormack & Collins, 2010; Nilsson & Townsend, 2010; Njelesani et al., 2015). In Njelesani et al.'s review of this concept they asserted that reflexivity in practice will protect our client centredness, by dissuading occupational therapists from choosing *"normal occupations"* replete with assumptions about independence or other societal attitudes (Njelesani et al., 2015). Increased representation of the person is needed in OT practice to ensure true client centred practice and meaningful participation for the clients with whom we work. Further, it evokes a need to consider how occupational therapists working with the person are part of this quest for participation. Failure to fully address the environment, including interactions with professionals, will likely compromise our client centredness, depleting occupational potential and possibilities.

6.2.2 Categorisation of Occupation and the Right to Occupation

Participants in this study chose occupations to promote their health, encompassing restorative occupations that focused on the nature of being and spending time with others. They experienced these sometimes as health promoting or diminishing, affording opportunities to be, belong and become. Restorative occupations included taking care of basic needs in managing diet, sleep and pace of routine, adjusting their occupations and spaces accordingly to access these. Restorative occupations facilitated being and belonging for participants. Other studies have captured similar findings however, described accessing or adjusting choices to include restorative occupations, with alternative terms that could imply judgement (Nagle et al., 2002; Sutton et al., 2012). Findings from this study did not view restorative occupation as disengagement but as engagement in occupation. These rights were mostly afforded by their environments, however with great effort and reflection on behalf of the participants. Regardless of the words used, all authors highlighted the choice available to participants, as was the case in the current study. Using restorative

however may offer an alternative term, free of judgement, while clarifying meaning. This growing body of support for choice in occupation, only strengthens the role of OT and OS in advocating for occupational rights. Further, through this knowledge, it could further distance the discipline and the profession from *"arbitrary categorisation"* of occupation which may diminish meaning and perpetuate judgement of some occupations over others (Njelesani et al., 2015; Reed et al., 2011; Wilcock, 1999). For example, the traditional categorisation of self-care work, and leisure may be unable to house restorative occupations and so by its lack of inclusion devalue it and limit attention afforded to it in practice. One specific restorative occupation embraced by Dave, Jane and Tim was that of meditation, as facilitated by both their home and community environments. Meditation was encouraged by the participants' peers and used to create time for being, or as Dave described, contemplating. As well as managing distress, this was mostly used to improve health and relationships. This finding prompts wider consideration of how visible demonstration of occupation may be perceived as only indicating health. Occupational therapists should also be cognisant of how they discuss *"health promoting"* or *"typical"* occupations with the people with whom they work and within wider arenas so as not to privilege some occupations over others.

Dave, Tim and Jane's accounts illustrated the importance of significant others in their lives, for collaborating in creative occupations and pursuing co-occupation to improve health. The participants described adjusting the frequency of contact with others while also highlighting the meaning of having others for support and belonging. Poignantly, mental health supports group created meaning for all three participants, creating a sense of relief in sourcing others with shared experience of mental health disability, receiving acceptance and belonging. All occupations chosen by participants appeared important for identity expression, primarily in experiencing normality and belonging. Even, occupations that did not involve others per se, such as meditating alone, were seen to enhance relationships through achieving personal calm. The findings of this study convey the importance of addressing being in OT practice, in order to meet the belonging needs of service users.

The occupations chosen by participants in this study did not fit neatly into the traditional categories of self-care, work and leisure. This was evident in how, they

chose creative and restorative occupations, creating meaning for participants in connecting with others, improving health and experiencing normality. Categorisation may diminish meaning (Hammell, 2004; Hitch et al., 2014b; Unruh, 2004). Reed and colleagues' (2011) review of existing literature on meaning, discussed the restriction by historical categories of occupation in progressing understanding of both the meaning attached to occupation and the experience of engaging in it. This resonates with Hammell's (2017), position calling for the profession's reconfiguration of the rigid categorisation of occupation, encompassing the role of belonging. The findings of the current study encourage occupational therapists to assert our client centred ideals to enable those with whom we work to create meaning through preferred occupations, and to avidly adopt reflection to consider how our terminology can promote or hinder experience of belonging.

6.2.3 Occupational Possibilities and the Capabilities Approach

Participants in this study, experienced complex encounters within their social worlds, recounting experiences of inclusion and exclusion, sometimes the result of combined stigma, ableism and their own mental health distress. Restrictions in their occupational possibilities occurred with experiences of exclusion diminishing feelings of belonging within their communities. The participants' narratives generated discussion of the normative ideals underlying disability representation in wider society. The findings of the current study resonate with other studies detailing the ways in which ableism and normative ideals about disability impact participation and identity (Asaba & Jackson, 2011; Hamer et al., 2014; Hamer et al., 2017; Salmon, 2013). Saliently *"practices of inclusion",* a term adopted by Hamer et al. (2014), were evident, in this study's findings. All three participants found solace within their mental health support groups, acknowledging the freedom and acceptance on receiving recognition from others who shared their experiences. Accessing identity groups was a strategy adopted by disabled youth to *"disrupt stigma",* generating belonging through enduring friendships (Salmon, 2013). The findings of the current

study, coupled with the prevalence of ableism reported by others, conveys the importance of access to affirming environments to experience belonging.

Participants in this study all realised their right to third level education, with this pursuit, transforming their lives, despite earlier experiences of exclusion within educational settings. They experienced belonging within these environments despite also experiencing episodes of exclusion. The rate of successful third level education for participants in this study contrasts with the 24.5% documented for people with disabilities in the Irish Disability Strategy (Department of Justice, 2017). Further research regarding the impact of this environment, particularly how it affords or restricts occupational possibilities and experiences of becoming and belonging is indicated. Further, additional interviews with these participants centring on this experience may have revealed greater insights into how this occupation shaped their identities.

Increasingly, scholars in OS are calling for social responsiveness from the discipline and from OT, imploring engagement with policy and rights to create just access to occupation and ultimately health (Boland & Cunningham, 2019; Hocking, 2017; Laliberte Rudman & Aldrich, 2017). Much of this discussion centres around the involvement of scholars and occupational therapists within the socio-political spheres of the person's environment. Although participants in this study identified episodes of exclusion and stigma, they too felt obliged to contribute to their communities and become who they wanted to be through occupation. These scholars map out the remit of OS in redressing the effects these injustices using core skills in occupation-base practice, client centredness and harnessing enabling environments. Within mental health services, there is the opportunity to direct funding and attention to create meaningful occupational possibilities. As Sutton, Hocking and Smythe (2012) assert, echoing Rebeiro's (2001) earlier stance, that personally tailored occupations for *"being"* are more enabling than those which are prescribed. Operationalising theoretical ideas of enablement, Lipskaya-Velikovsky et al. (2016) advocate for the significance of occupational therapists within the therapeutic milieu for people with schizophrenia to protect access to *"occupation-based services"* enabling participation. Adding that these interventions should also

encapsulate occupations that involve others within the person's environment (Lipskaya-Velikovsky et al., 2016). Further, Nilsson and Townsend (2010) encouraged occupational therapists to lead in expressing their client centredness, championing enablement across the healthcare sector and reducing restrictions to participation for instance, through redevelopment of programmes to include real life occupations and collaboration with service users and their supporters. In summary, the findings of the current study, alongside the findings and assertions of others, emphasise the importance of OS and OT to understand and advocate for access to occupation for people with a mental health disability.

6.3 Study Limitations

This was a small sample size, preferable for the research methodology but limiting potential for transferability to other cultures. Participants were all white Irish, and all had attended third level education. Although from different backgrounds, and as far as I was aware the participants did not know each other, they may have had similar attitudes and beliefs given their shared commitments to attend their mental health support groups. I would have preferred prolonged contact with the participants to gain greater insights into their occupational worlds and increased opportunity for collaboration within the research process, however, time was not permitting given my part-time research capacity and scope at this degree level. Further interviews, as Reynolds (2003) highlighted in her study, would have provided more frequent member checking coupled with a more whole narrative, adding to this research's credibility. With others asserting the benefit of prolonged contact toward a more consistent and complete narrative (Blank et al., 2015; Sakiyama et al., 2010).

6.4 Chapter Conclusion

This study has contributed to the knowledge of occupation as it is experienced by people with a mental health disability. Participants narratives illustrated their use of and consideration of both paid employment and creative occupations to experience normality and belonging, ultimately shaping their identities. Participants used occupation to promote their health and considered some occupations to be health promoting despite societal conventions contrary to this. Experiences of inclusion and exclusion were articulated by the participants, powerfully portraying the presence of stigma and ableism existent in their everyday lives, however, connectivity with others was complex. Co-occupation, recognition and acceptance enabled inclusion, whereas stigma, marginalisation and ableism fostered exclusion. Overall occupation was determined as significant within the lives of the participants in conveying their health, normality and belonging to their worlds.

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Appendixes

Appendix 1: Ethics Approval Confirmation

UCC
Coláiste na hOllscoile Corcaigh
University College Cork, Ireland

Oifig an Leas - Uachtaráin Taighde agus Nuálaíochta
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Caoileann Cassidy
Occupational Therapy Manager, Mental Health
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Vergemount Hall
Clonskeagh Hospital
Clonskeagh Road, Dublin 6

10th March 2020

Dear Caoileann

Thank you for submitting your research project, Log 2018-201 (entitled "Navigating meaningful occupation in the community, the importance of belonging.") to SREC for ethical perusal. I am pleased to say that we see no ethical impediment to your research as proposed and we are happy to grant approval. Approval date was 18th December 2018.

We wish you every success in your research.

Yours sincerely,

Ciara Heavin,
Chair of Social Research Ethics Committee

Professor Anita R. Maguire BSc PhD CChem MRSC
Vice President for Research and Innovation

Ollscoil na hÉireann, Corcaigh
National University of Ireland, Cork

Appendix 2: Research Flyer

UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Do you want to share your Story?

What is this research about? I want to hear about your experience of engaging in occupations in local, familiar places to you, especially how this might have affected your experience of belonging to your social groups, community and the relationship of this to your mental health.

What is an Occupation? I define occupations as: "…. Culturally and personally meaningful activities…", (Jackson, 1996, in Zemke and Clark). Examples of everyday occupations include: going for a coffee listening to music, using transport.

Who can take part? Taking part in this study is completely voluntary. If you are interested in becoming involved I will make sure you have been fully informed about what is expected of you and that I have your written consent to take part. To take part you need to be over the age of 18 and have a self-reported mental health disability.

What happens if I choose to take part?

- If you decide to take part in this study we will need to meet three times in total, in a venue of your choice, for 1-2 hours each time.
- During the first meeting I will ask you questions about which occupations you choose to spend your time on now and in the past, as well as which occupations are done with others (such as family or friends) in your local area and community. I will record these interviews but will take out any identifying information.
- In our second meeting I would like to do an occupation of your choice within your local area. At times I might take notes, if you are comfortable with this.
- Finally, we will finish with one more interview to reflect on how your occupations have influenced your identity, experience of belonging to your social groups, community and how this relates to your mental health.

About Me	Occupational Science and Occupational Therapy
My name is Caoileann Cassidy and I'm an Occupational Therapist working in Mental Health. I am undertaking a Masters by Research in Occupational Therapy at the Department of Occupational Science and Occupational Therapy at UCC. **I want to learn more about the relationship between what we do or how we spend our time and our mental health.**	Occupational Science is an academic discipline dedicated to researching occupation. Occupational Therapy is a clinical, client centred health profession working with people across their lifespan. Occupational therapists focus on using occupation to support people in changing their lives and health.

If you are interested in taking part I would really like to hear from you. You can contact me below:





Email: 118224233@umail.ucc.ie

Appendix 3: Information Sheet

INFORMATION SHEET

University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Thank you for considering participating in this research project. The purpose of this document is to explain to you what the work is about and what your participation would involve, so as to enable you to make an informed choice.

The purpose of this study is to hear from people with self-reported mental health disability regarding their experience of engaging in occupations in their social environments. For this study occupations are defined as: *"…. Culturally and personally meaningful activities in which individuals partake on a daily basis or at various times throughout their lives",* (Jackson, 1996, in Zemke and Clark).

Should you choose to participate, you will be asked to complete two one-to-one interviews and one observation with the researcher. The interviews will be audio-recorded and kept confidential using a password protected audio device and participant code. The interviews are expected to take 60-90 minutes to complete. The observation may take longer and will occur in a familiar environment to you as we both engage in an occupation of your choice so that I can gain further insights into your experience of engaging with occupations in your community local environment(s).

Participation in this study is completely voluntary. There is no obligation to participate, and should you choose to do so you can refuse to answer specific questions or decide to withdraw from the interview. Once the interview has been concluded, you can choose to withdraw your details at any time in the subsequent two weeks.

All of the information you provide will be kept confidential and anonymous, and will be available only to me, the researcher and my two supervisors. The only exception is where information is disclosed which indicates that there is a serious risk to you or to others. Once

the interview is completed, the recording will immediately be transferred to an encrypted laptop and wiped from the recording device. The interview will then be transcribed by the researcher, and all identifying information will be removed. Once this is done, the audio-recording will also be deleted and only the anonymized transcript will remain. This will be stored on a password protected laptop and in line with UCC guidelines, data will be kept for ten years before being destroyed by me through deletion from my password protected UCC google drive. The information you provide will be the results in my master's thesis and may be part of future research publications and/or conference presentations.

I do not intend to cause any distress to participants however by reflecting on life events some of the discussion may cause potential distress to you. This is because some of the topics raised during the interview may include sensitive personal information. Should you wish to do so, you can choose not to answer questions and bring the interview to an end at any time. At the end of the procedure, I will discuss with you how you found the experience and how you are feeling. Should you experience distress arising from the interview, the contact details for support services provided below may be of assistance:

1. **Samaritans Ireland.** Call Freephone: 116 123, Text: 087 2 60 90 90 (standard text rates apply), Email: jo@samaritans.ie (RoI)
2. **Pieta House.** Call Freephone: 24-hour suicide helpline on 1800 247 247. Text HELP to 51444 (standard message rates apply)
3. **H.S.E. Mental health services:** If you have been (or are currently) supported by a mental health team, go to the Emergency Department or contact the service you are attending and ask for an appointment as soon as possible.

This study has obtained ethical approval from the UCC Social Research Ethics Committee.

If you have any queries about this research, you can contact me at:

Researcher: Caoileann Cassidy **Email:** 118224233@umail.ucc.ie

Supervisors:

- Dr. Helen Lynch **Phone:** 00353-21-4901535 **Email:** h.lynch@ucc.ie
- Professor Jeanne Jackson **Phone:**00353-21-4903000**Email:** j.jackson@ucc.ie

If you agree to take part in this study, please sign the consent form on page 3.

Appendix 4: Consent Form

Consent Form



I……agree to participate in Caoileann Cassidy's research study entitled:

"Navigating meaningful occupation in the community, the importance of belonging."

The reason for this form is to help you decide whether you would like to participate in this study.

- The purpose and nature of the study has been explained to me in writing.
- I confirm that I have had an opportunity to ask questions
- I am participating voluntarily.
- I give permission for my interview with Caoileann to be audio-recorded.
- I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.
- I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.
- I understand that anonymity will be ensured in the write-up by disguising my identity.
- I understand that the anonymised data from my interview will be kept for ten years on an encrypted computer.
- I understand that disguised extracts from my interview may be quoted in the thesis and

any subsequent publications if I give permission below:

(Please tick one box:)

I agree to quotation/publication of extracts from my interview ☐

I do not agree to quotation/publication of extracts from my interview ☐

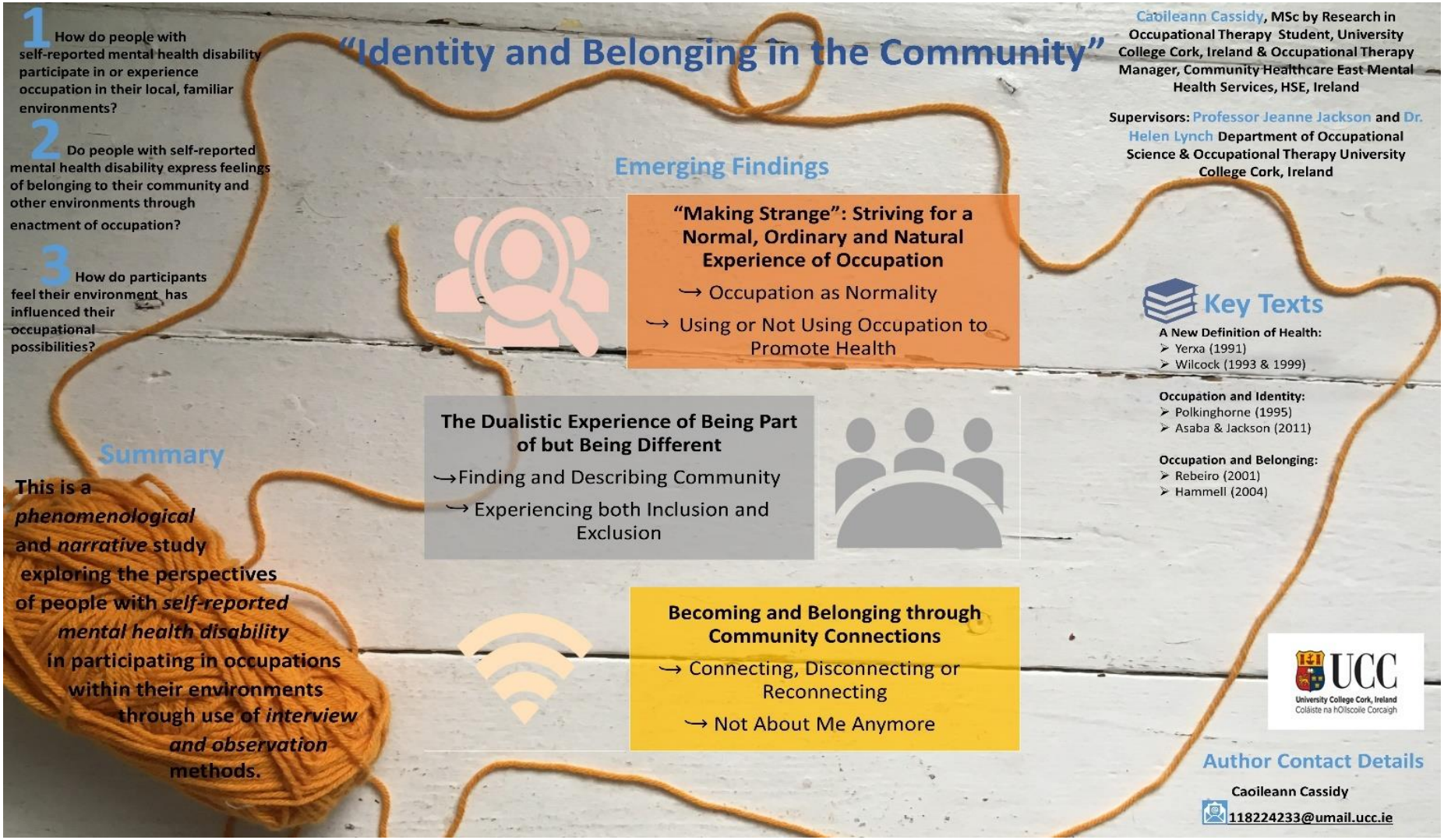
Signed: …….. Date: ……..

PRINT NAME: ……..

PRINT NAME: ……..

<u>Appendix 5: Poster Presentation:</u> "Identity and Belonging in the Community"

Presented at Occupational Science Europe 30th of August 2019



Appendix 6: Interview Schedule 1

Note: Remind each participant of their right to withdraw at any point during the research. Discuss each participant's right to decline answering any of the questions and availability of additional supports as needed.

Proposed Time Needed: 60-90 minutes
Interview Venue: To be determined collaboratively with participant and researcher.

Introduction:

- Tell me about how you spend your time in a typical day. What do you do everyday? (*prompts: tell me more about that, where do you do that? Who do you do it with? How often do you do that? What does that mean to you?)*

Further Questions:

- Can you tell me about your experience of engaging in occupations in your social environment like your local area, with your family or with friends? Who and what kinds of things are in your social world?

- Talk me through the most recent occupation or activity you did with other people? *(prompts: what does that mean to you? How did this come about? How did you get involved in this?)*

- What does belonging or being part of something mean to you? Where do you feel you belong or a part of a group? Can you tell me more about this?

- What kinds of occupations do you think require other people? Can you tell me more about this?

Probing Questions:

- What did that feel like?
- What did you get from it?
- How did people react?
- What kinds of places did you do things in?

Conclusion:
Is there anything else you would like to add?
How are you feeling after the interview? Here is some information about additional supports should you need them.
Thank you for taking the time to talk with me and share your experiences.

Planning the Collaborative Occupation:

As you know part of this study involves doing something together in your local area so that I can see your social world. This will give us much richer information about your culture and what occupations are meaningful to you.

Your social world might include anywhere were you engage with a group of people with shared interests, circumstances or culture. This may be a group where you share an occupation such as a book club, gym or local supermarket. Some things to consider include:

- Cost
- The impact of the researcher on this experience - ? intruder to the norm
- Boundaries

Appendix 7: Interview Schedule 2

Note: Remind each participant of their right to withdraw at any point during the research. Discuss each participant's right to decline answering any of the questions and availability of additional supports as needed.

Proposed Time Needed: 60-90 minutes
Interview Venue: To be determined collaboratively with participant and researcher.

Introduction:

- Tell me about your experience of _____ that we completed. (*Prompts: how do you think it went? How did you feel? Would you have changed anything?)*

Further Questions:

- You mentioned in interview 1 that you did _____ . Can you tell me more about this?

- Have you ever felt like you didn't belong somewhere? Where was this and what were you doing? (*prompts: groups, families, communities, online, institutions e.g schools, workplaces).*

- Have you experienced exclusion from occupations in your social environments? *(Prompts: What happened in this situation? What do you think impacted this outcome?*

- Have you changed what you spend your time doing as a result of exclusion? *(Prompts: what did you change? Why did you change it? How do you feel about it now?)*

Probing Questions:

- What did that feel like?
- What did you get from it?
- Can you tell me more about that?

Conclusion:

- Is there anything else you would like to add?

- How are you feeling after the interview? Is there anything you need to talk about? Here is some information about additional supports should you need them.

Thank you for taking the time to talk with me and sharing your experiences.